1994

Quality of Life Predictors: Heart Transplant Spouses

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Recommended Citation

Collins, Eileen G., "Quality of Life Predictors: Heart Transplant Spouses" (1994). *Dissertations*. 3472.
https://ecommons.luc.edu/luc_diss/3472

LOYOLA UNIVERSITY CHICAGO

QUALITY OF LIFE PREDICTORS: HEART TRANSPLANT SPOUSES

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL OF ARTS AND SCIENCES
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

SCHOOL OF NURSING

BY

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CHICAGO, ILLINOIS

MAY 1994

ACKNOWLEDGMENTS

I would like to acknowledge my dissertation committee, Anne Jalowiec RN, PhD (chair), Gerald Mozdzierz PhD, Donna Rankin RN, DNSc, and Jack Kavanagh PhD, for their encouragement throughout this dissertation process.

I would like to thank Dr. Anne Jalowiec for her willingness to facilitate a link with her NIH study site in Alabama. In addition, her zest for research has inspired me to pursue my own research aspirations in nursing and quality of life.

Lastly, I would like to acknowledge Connie White-Williams RN, MSN, Heart Transplant Coordinator at the University of Alabama-Birmingham, for her support in obtaining the necessary subjects for this study.

DEDICATION

I would like to dedicate this dissertation to my Mom and Dad, my brother John and his wife Cathy, my brother James and his fiance Mary, my friend Mary, my husband Bill, and my children Claire and Michael. Their encouragement, love and understanding helped me through the last four years.

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CHAPTER I

STATEMENT OF THE PROBLEM

Introduction

Over the past decade, heart transplantation has become a viable treatment option for patients with end-stage congestive heart failure. The number of patients waiting for and receiving heart transplants (HT) has grown exponentially. Prior to 1980, less than 360 heart transplants were performed (Kriett & Kaye, 1991). Just 12 years later, December 1992, 25,659 heart transplants had been performed throughout the world (Kaye, 1993). As of December 1993, 2834 patients were actively awaiting heart transplantation (UNOS, 1994). The wait for a heart transplant has increased because of insufficient donors. In 1988, UNOS reported that 35.1% of the patients waiting for a heart transplant waited six months or more. In just three years, 1991, 52% of the patients were waiting six months or longer and 27% were waiting more than a year (UNOS, 1994). Thus, patients are waiting for longer periods of time for donor hearts to become available.

To date, 79% of HT patients can expect to survive one year post-transplant (Kaye, 1993). With advances in technology, these statistics may improve over the years. Although the statistics are impressive, researchers have recognized a need to study HT patients at great length because the heart transplant process can be physically, emotionally, and economically draining. As a result, many researchers have focused their research efforts on studying quality of life (QOL) in this population (Bohachick et al., 1992; Brennan, Davis, Buchholz, Kuhn, & Gray, 1987; Bunzel, Grundbock, Lackovics, Holzinger, & Teufelsbauer, 1991; Caine, Sharples, English, & Wallwork, 1990; Dew et al., 1991; Grady, Jalowiec, Grusk, White-Williams, & Robinson, 1992; Harvison et al., 1988; Hunt, 1985; Lough, Lindsey, Shinn, & Stotts, 1987, 1985; Mai, McKenzie, & Kostuk, 1990; Meyerowitz, Vastering, Muirhead, & Frist, 1990; Muirhead et al., 1992; O'Brien, Buxton, & Ferguson, 1987; Packa, 1989; Paris et al., 1992; Walden et al., 1989).

Although most health care personnel recognize that heart transplantation can be taxing on the family as well as on the patient, only three studies were found that addressed the impact of heart transplantation on the spouse and/or family (Buse & Pieper, 1990; Mishel & Murdaugh, 1987; Nolan et al., 1992). Buse and Pieper (1990) used retrospective data to assess the impact of waiting for a heart on the spouse. Mishel and Murdaugh (1987) used grounded theory to study the effect of heart transplantation on families. However, only 35% (N = 7 of 20) of the family members were waiting for a transplant and all were actively participating in a support group. Lastly, Nolan et al. (1992) studied stress and coping in heart transplant family members awaiting transplantation, but did not report the overall impact on the family member's quality of life.

Although there were weaknesses in the studies above, they each had some interesting findings, thus suggesting that further research still needs to be done. Although Buse and Pieper (1990) assessed the pre-transplant retrospectively, spouses of HT patients reported high levels of stress for this time period as measured by the Subjective Stress Scale. Similarly, Nolan et al. (1992) reported that 53% of the family members of HT candidates reported moderate levels of stress and 47% experienced low stress. Mishel and Murdaugh (1987) reported that families of HT candidates became totally immersed in the process so that their entire life focused on their loved one waiting for a heart donor.

Several other studies have examined the effect of illness other than heart transplantation on the spouse's quality of life. Artinian and Hayes (1992) found that the following variables were significantly related to the spouse's quality of life: spouse's (subject's) ailments, the perception of their own health, affirmation support, social support, income, and the perception of the partner's health. Sexton and Munro (1985) found that subjective stress, money, the diagnosis of chronic obstructive pulmonary disease (COPD) and unemployment accounted for 49% of the variance in predicting quality of life in spouses of COPD patients.

others have reported increased physical and psychological difficulties in spouses of critically ill patients (Bohachick & Anton, 1990; Gilliss, 1984; Mathieson, Stam & Scott, 1991; Mayou, Foster & Williamson, 1978a; Stern & Pascale, 1979).

Significance of the Study

In summary, waiting for a heart can be a very stressful time for families because family members are physically and emotionally affected by their loved one's illness. As the wait for a donor heart increases, more patients will be taken care of at home and in hospitals for longer periods of time. As a result, quality of life for spouses may be compromised. In order to maintain support for the HT candidate as well as avoid further physical and emotional compromise for the spouse, it is essential to recognize what areas of life are affected by the HT experience so that appropriate interventions can be planned.

Although several researchers had studied various aspects of the effect of heart transplantation on the spouse, no study had specifically examined the impact of waiting for a heart transplant on the spouse's quality of life. This was the first study specifically assessing predictors of quality of life in spouses of heart transplant candidates. This study focused attention on the concerns and experiences of spouses of HT candidates as they assisted their patient partner through the wait for a heart donor.

Purpose of the Study

The purpose of this study was to identify predictors of quality of life for spouses of heart transplant candidates. Specific aims for this project were:

1. Identify stressors experienced by HT spouses during the wait for heart transplantation.
2. Identify coping mechanisms, coping ability, and family resources used by spouses of HT candidates to handle stress during the HT waiting period.
3. Assess the impact of the HT experience on spouses of HT candidates during the wait for a heart donor.
4. Assess levels of life satisfaction and perceived overall quality of life for spouses of HT candidates during the wait for heart transplant.
5. Determine differences in stress, coping, family resources, and QOL based on gender, work status, the patient's health status, and the impact of the transplant experience.
6. Determine the relationships between selected demographic and health-related variables, stress, coping, family resources, transplant impact, and QOL.
7. Determine predictors of quality of life for spouses of HT candidates.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

The purpose of this literature review is to provide background information pertinent to the implementation of this study. Specific areas addressed are:

1. The general concept of quality of life including a brief historical overview, definitions, and domains
2. Models of quality of life
3. Lazarus Model of Stress and Coping as a QOL conceptual framework for this dissertation
4. Quality of life in selected cardiac patients
5. Quality of life in families
6. Gaps in the literature
7. Preliminary study done by the investigator.

Quality of Life

Historical Perspective

Quality of life has been a concern for philosophers and historians for a long time. Some authors equate happiness with quality of life (Beckman & Ditlev, 1987; Dubos, 1976). Aristotle, in Ethica Nicomachea, talks of seeking happiness and the good life. Thomas Jefferson specifically included the pursuit of happiness as a right delineated in the United

States Constitution. According to Spitzer (1987), the term "quality of life" entered the American vocabulary sometime between World War II and the initiation of Lyndon Johnson's Great Social Programs. The term was used to mean the good life and referred to economic prosperity.

A reference to quality of life is implied in the World Health Organization's (WHO's) definition of health. WHO defines health as not only the absence of illness but also a state of physical, mental and social well-being (1947). The focus of the WHO definition is not only on the disease process but on the individual's overall sense of well-being or quality of life.

A few QOL studies were undertaken in the 1950s and 1960s. Of note, in 1957, a national survey by the Joint Commission on Mental Illness and Health was conducted to look at determinants of happiness. The Joint Commission wanted to know why people worry, what their outlook for the future was, and in general examine the ways in which people live (Gurin, Verhoff & Feld, 1960). This is the first time that people were asked about their perception of life in general. In 1965, Cantril made a major contribution by developing the Cantril Self-Anchoring Scale. The scale measures the individual's perception of life with the individual as the comparison or anchor. This is a major milestone in the quality of life literature in that the individual serves as his/her own control.

It was not until 1973 that medicine formally recognized the importance of quality of life research. Bunker and Wennberg wrote an editorial in the _New England Journal of Medicine_ stating that medicine needed to look at improving quality of life--relief of disability, discomfort and disfigurement, not merely mortality. However it was not until 1983 that QOL was designated a formal subject heading in the _Cumulative Index to Nursing and Allied Health_. Since then, the number of quality of life citations has grown dramatically. In 1991 alone, the _Cumulative Index to Nursing and Allied Health_ listed 102 quality of life citations.

Conceptual Clarity

Definitions. Precise definitions of quality of life have been elusive, so currently, there is no universally accepted definition for this concept. For many studies, the author's definition of quality of life must be inferred by the variable(s) he/she chooses to measure. Consequently, quality of life may refer to a variety of topics such as physical function, psychological complaints, physical or psychological symptoms, general feelings of well-being, sexual functioning and the ability to perform activities of daily living.

Many authors have used life satisfaction and/or happiness to define quality of life (e.g., Beckman & Ditlev, 1987; Burckhardt, Woods, Schultz & Ziebarth, 1991; Campbell, Converse & Rodgers, 1976; Cella & Tulsky, 1990; Dubos, 1976; Ferrans, 1990; Ferrans & Powers, 1985; Institute of Medicine, 1986; Miller, 1983; Oleson, 1990; Shumaker, Anderson & Czajkowski, 1990).

Campbell et al. (1976) provide an interesting comparison of the connotations associated with satisfaction and happiness. They note that the correlation between satisfaction and happiness is usually about 0.5. Given this correlation, there are a number of people who are happy but not satisfied, or satisfied but not happy with their life. Happiness connotes a short-term gaiety and elation. It is the product of the presence of positive feelings and the absence of negative feelings. Happiness suggests a feeling or affect. Satisfaction, conversely, is a perceived discrepancy between aspiration and achievement, ranging from the perception of fulfillment to that of deprivation. Satisfaction therefore implies a cognitive or judgmental experience.

Campbell et al. (1976) conclude that quality of life is the same as life satisfaction. This may not be the case. Grady et al. (1992) presented data that differentiates quality of life and life satisfaction. When subjects were asked to rate their quality of life and life satisfaction, they gave two different ratings. Ninety-six percent of post-heart transplant patients rated their life satisfaction as high, whereas only 58% rated their quality of life as good. This shows that quality of life and life satisfaction are related but are not the exact same thing.

Some authors (Calman, 1987; Enquist, 1979; Sartorius, 1987) view quality of life as a function of goal attainment. This type of definition may be problematic since a person may fulfill their goals and aspirations and still not be satisfied with life. Conversely, a person may not have fulfilled their goals/aspirations but still perceive satisfactory quality of life.

An overall evaluation of well-being provides a close approximation of the person's perception of quality of life. Aaronson (1989) believes that the use of one item, asking the person to rate their overall quality of life, may be the most reliable indicator of quality of life. Indeed, many recent QOL studies include an overall global measure of life quality.

Some researchers imply that quality of life is only physical function. This is typical of many early medical studies when quality of life was reported as physical function and mortality. This limited scope however is changing.

Domains. Throughout the QOL literature, authors and researchers have organized quality of life variables into several categories or life domains. Flanagan (1982) asked 3000 adult Americans to identify major factors affecting their quality of life. Approximately "6500 critical incidents were collected, each reporting a time when something was actually observed to have a significant effect either positively or negatively on the [subject's] overall quality of life" (p. 57). These 6500 critical incidents were classified into 15 factors and ultimately into five categories or domains of quality of life. The five domains are: 1) physical and material well-being; 2) relations with other people; 3) social, community, and civic activities; 4) personal development and fulfillment; and 5) recreation.

Aaronson (1991) states that there is growing consensus on a minimum set of domains to be incorporated into a QOL assessment. "These include physical functioning, disease-related and treatment-related symptoms, psychologic functioning, and social functioning" (p. 846). Wenger, Mattson, Furberg, and Elinson (1984) identify three factors influencing quality of life in the medically ill: functional capacity, perceptions, and symptoms. Ferrans and Powers (1985) delineate four domains of quality of life: physical functioning, psychological/spiritual, social/economic, and family. In summary, the primary domains cited in the literature include: physical functioning, psychological functioning, and social functioning. Spiritual functioning, economic hardships, and symptomatology can be subsumed under one of these categories.

Jalowiec (1990) and Ferrans (1990) compiled a table of variables that could be measured under each domain. Jalowiec divided the domains into physical, psychological and social. Ferrans divided the domains into health and physical functioning, psychological/spiritual, social and economic, and family. The two tables have been combined in Appendix A to form an extensive list of variables that could possibly be measured in a quality of life inquiry. All variables, from the two tables, were listed under physical, psychological, or social as suggested by Jalowiec (1990) and Aaronson (1991). Disease-specific variables were not included in this general overview. The family domain of Ferrans was incorporated into the social domain.

Jalowiec argues (1990) that the impact of health or illness on certain aspects of a patient's life may create a domino effect so that other aspects of the patient's life may be indirectly affected. Thus when measuring quality of life, one may need to broaden the variables being measured to include aspects of life indirectly as well as directly affected by the illness.

Models of Quality of Life. Conceptual weakness seems to be the major problem in QOL research. Currently, there is no accepted definition of quality of life and thus measures of quality of life have been ad hoc in nature. However, there are some recurrent themes throughout the literature which can serve as stepping stones to theory development. Indeed, a handful of researchers have attempted to build models of quality of life.

There seems to be general agreement that quality of life is multidimensional. Campbell et al. (1976) proposed a model of quality of life based on life satisfaction in multiple domains of life (see Appendix B). Campbell et al. maintained that a person's satisfaction with a particular domain of quality of life is dependent upon his/her evaluation of various attributes of that domain. How the person assesses the attribute is dependent upon how he/she perceives the attribute versus a standard against which he/she judges the attribute. The assessment of satisfaction is influenced by the individual's personal characteristics, past experiences, and coping and adaptive behaviors.

Campbell et al. (1976) proposed four phases as antecedents to the model: objective attributes, perceived attributes, evaluated attributes, and satisfaction with the domain. This seems cumbersome. Perception implies that there is an objective or subjective reality to be perceived. Additionally, satisfaction implies that an evaluative process has taken place. Further, for perception to occur, some sort of evaluation must take place. Thus, reducing the antecedent four phases of the model to perception and satisfaction would simplify the model but still maintain the meaning of the model. Next, coping and adaptive behavior are the outcomes of the model. Coping and adaptive behaviors influence the perception of various attributes of a particular domain; therefore, there should be a feedback loop to the beginning of the model. In general however, this is a workable model and deserves more attention in the QOL literature.

Padilla and Grant (1985) proposed an oncology nursing care model using quality of life as an outcome measure. They proposed various domains (i.e., psychological well-being, social concerns, body image concerns, physical well-being, diagnosis/treatment response) as dependent outcome variables of nursing care. The independent variables are various aspects of the nursing process. The independent and dependent variables are mediated by the patient's perception of those variables (see Appendix C). Padilla and Grant also proposed that personal characteristics as well as disease characteristics are extraneous variables that influence the perception of quality of life.

The Padilla and Grant model, taken as a nursing care model, makes some unrealistic assumptions. First, it makes the assumption that a nurse be present for satisfaction with the domains to be achieved. Second, other disciplines (e.g., medicine, psychology, physical therapy) are left out of the model. Certainly, it would be naive of nursing to assume that it alone can accomplish everything in terms of patient care and satisfaction with outcomes. Lastly, the independent variables do not necessarily coincide with the dependent variables. For example, perception of a caring attitude by a nurse does not necessarily lead to psychological well-being of the patient. In summary, this model does not seem realistic or workable. The notion, however, of using QOL domains as outcome measures for nursing care does seem plausible.

Graham and Cowan published a QOL model for patients with chronic illness delineating antecedents, mediating variables, and consequences (Cowan, Graham, & Cochrane, 1992). Severity of disease, aggressiveness of treatment, and socioeconomic level comprise the antecedents; manifest symptom distress, functional alterations, and cognitive adaptation are the mediating variables; and perceived quality of life constitutes the outcome variable (see Appendix D).

Thus, Graham and Cowan provide a measurable model with antecedents, mediating variables, and consequences. Aaronson et al. (1991) suggest that "the usefulness of the models will be enhanced when the links among the variables studied (e.g., antecedent, mediating, modifying) and quality of life outcomes are made explicit" (p. 842). In this respect, Graham and Cowan are to be applauded. In addition, they demonstrate positive and negative relationships between the variables, providing further support for their model. Unfortunately, their sample size was too small to use more powerful statistics such as path analysis or LISREL to test the model.

Conceptually, Graham and Cowan's model makes some philosophical assumptions that can be questioned. First, their model "pathologizes" the concept of quality of life. With the exceptions of socioeconomic level and cognitive adaptation, the other variables (severity of disease, aggressiveness of treatment, manifest symptom distress and functional alterations) imply negativity or pathology. The quality of a person's life, even though chronically ill, may not be defined by or revolve around the illness. The authors maintain that these factors _influence_ quality of life and do _not_ define quality of life. In effect however, by not including other influencing factors, the authors assert that these factors do define quality of life.

The second major criticism of the Graham and Cowan model is that the model does not allow for other influencing factors, such as psychological disposition, personality factors, or life experience. The model begins at the disease process. It makes the unwritten assumption that prior events do not influence present circumstances.

Lastly, the Graham and Cowan model is unidirectional. The model, in this author's opinion, should have allowed for bidirectionality and feedback loops. For example, positive cognitive adaptation may decrease one's perception of their functional alterations. Similarly, a positive or negative perception of quality of life may influence one's perception of the severity of illness. In summary, although this model delineates antecedents, mediating variables, and consequences, as suggested in the literature, it is too narrow in scope for general use and does not allow for feedback of perceptions.

Lough (1988) proposed a conceptual model for HT patients beginning with the diagnosis of heart failure and ending with satisfaction with quality of life post-transplant. Lough lists variables along each step of the disease trajectory (see Appendix E) which are symptoms or problems that HT patients are known to have. Increases and decreases in symptoms or variables have been postulated as affecting the QOL outcome.

Lough's model however, does not describe any relationships among the independent variables. Does an increase in one area decrease function in another area? There is no place in the model for adaptation or coping with the various stressors. This model is also unidirectional; thus it does not allow for reassessment of quality of life once a degree of satisfaction has been reached. In summary, Lough compiles a comprehensive list of problems and benefits of heart failure and transplantation along the disease pathway but does not define or acknowledge an interaction among the variables.

Conceptual Framework for Dissertation

Quality of life has also been studied from a stress and coping perspective (Artinian, 1991; Artinian & Hayes, 1992; Beach et al., 1992; Bergman, Sullivan, & Sorenson, 1991; Bihl, Ferrans, & Powers, 1988; Ebbeson, Guyatt, McCartney, & Oldridge, 1990; Gilliss, Neuhaus, & Hauck, 1990; Hurny et al., 1992; Leavitt, 1990; Meyerowitz et al., 1990; Miller & Wikoff, 1989; Muirhead et al., 1992; Sexton & Munro, 1985; Voepel-Lewis, Starr, Ketefian, & White, 1990). Given the stressful nature of the heart transplant process, it makes conceptual sense to approach quality of life in spouses of HT patients from a stress and coping perspective. In addition, the QOL models cited previously have serious weaknesses, thus making them inappropriate for this study.

Therefore, the Lazarus and Folkman Model of Stress and Coping was adopted for this dissertation. Lazarus' model is a transactional model which "views the person and the environment in a dynamic, mutually reciprocal, bidirectional relationship" (Lazarus & Folkman, 1984, p. 293). What is a consequence at one point in time may be an antecedent at another point in time. The Lazarus and Folkman (1984) model has four major variables: stress, appraisal, coping, and adaptational outcome.

For the purpose of this discussion, stress is defined as a stimuli or stressor. Lazarus and Folkman (1984) describe three types of stressors: major changes, often catastrophic and affecting a large number of people; major changes affecting one or a few persons; and daily hassles. The authors state that a life-threatening or incapacitating illness may be considered a stressor which affects one or more persons.

Such a definition of stress, however, does not allow for individual differences in the evaluation of the particular event. The authors further define psychological stress as a "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. 21). Thus, in order to understand the differences between individuals, one must take into account the cognitive processes which mediate the event and the reaction to the event. Lazarus and Folkman call this process cognitive appraisal.

Lazarus and Folkman (1984) delineate three types of appraisal: irrelevant, benign, and stressful. When an encounter is irrelevant, it has no value or implication for the person's well-being and nothing is gained or lost by the transaction. Benign-positive appraisals occur if the response to the event is positive or if the individual's well-being is enhanced by the encounter. Stress appraisals include harm/loss, threat, and challenge. In harm/loss appraisals, there has been some damage to the person already. This can be in the form of an incapacitating illness or loss of a loved one. Threat appraisals concern potential harm/loss appraisals that have not yet taken place but are anticipated in the future. Challenge appraisals are similar to threat appraisals except that there is some potential for gain or growth from the encounter. Thus, through the cognitive appraisal process, the individual evaluates the significance of an event on his/her overall well-being.

Personal and situational factors which influence appraisal are further delineated by Lazarus and Folkman (1984). Personal factors which influence appraisal are commitments and beliefs. Commitments define what has meaning or importance to the individual. Beliefs are pre-existing notions about reality that the individual brings to an encounter. Situational factors which influence appraisal are novelty, predictability, event uncertainty, temporal factors and ambiguity. One can easily see that waiting for a husband or wife to be transplanted can be appraised as having great meaning to the person as well as being a great threat to the individual's well-being. To most, the situation is new, unpredictable, and uncertain. There is no set time before which the heart transplant will occur; it may be days before a heart becomes available or it may be years so one does not know exactly when the transplant will happen. Lastly, information is often gleaned from health care providers and the environment (e.g., hospital, doctor's office etc.) that may be ambiguous. For example, a spouse may be told that his/her patient partner is doing fine but extra medications may have been added to his/her regime, thus making the situation ambiguous for the spouse.

Coping is defined by Lazarus and Folkman (1984) as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Lazarus and Folkman postulate two broad classifications of coping behavior (problem-focused and emotion-focused) under which anywhere from 5-8 types of coping methods are included based on different factor analyses. Jalowiec (1991) describes eight types of coping styles: confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportant, and self-reliant.

Lazarus and Folkman (1984) state that the ways in which people cope are heavily influenced by the resources available to them. Some of the resources people draw upon in times of stress are money, help of other persons, or skills of various types. McCubbin and Comeau (1987) identify four main kinds of family resources to assist families in coping with crisis: esteem and communication, mastery and health, extended family social support, and financial well-being. Lazarus and Folkman (1984) list six categories of resources: health and energy, positive beliefs, problem-solving skills, social skills, social support, and material resources.

Lastly, Lazarus and Folkman (1984) note that stress, appraisal, and the coping process are of prime importance because of how the adaptational outcome is affected by them. They list three basic outcomes: functioning in work and social living, morale or life satisfaction, and somatic health. "Simply put, the quality of life and what we usually mean by mental and physical health are tied up with the ways people evaluate and cope with the stresses of living" (Lazarus & Folkman, 1984, p. 181). Thus, quality of life is a natural outcome of the stress and coping process.

Table 1 shows a visual depiction of how the Lazarus and Folkman Model of Stress and Coping was used for this dissertation. Due to sample size concerns, only the four major variables (stressors, appraisal, coping, and quality of life) in the model were tested. (Of note, this table includes <u>all</u> variables considered.)

TABLE 1

MODEL FOR STUDY ON QUALITY OF LIFE IN HEART TRANSPLANT SPOUSES USING THE LAZARUS STRESS AND COPING CONCEPTUAL FRAMEWORK

ANTECEDENT VARIABLES--MEDIATING VARIABLES--OUTCOME VARIABLES
STRESSORS APPRAISAL COPING QUALITY OF LIFE

STRESSORS	COPING
Duration of time patient on HT waiting list Spouse's perception of patient's health Patient's objective health status Spouse's health Spouse's employment status	Jalowiec Coping Scale Coping ability rating Family Inventory of Resources for Management
APPRAISAL	QUALITY OF LIFE
Spouse Transplant Stressor Scale Impact of the transplant rating question Overall stress rating	Ferrans and Powers Quality of Life Index Overall quality of life rating question

Quality of Life in Selected Cardiac Patients

For the purpose of this dissertation review, quality of life in two populations needs to be discussed. First, a review of quality of life in cardiovascular patients (heart failure, angina, and myocardial infarction) will be discussed. It is important to review this body of literature since this is the patient group with which the spouses are dealing during the transplant wait. Second, QOL of families will be reviewed. Related family literature will also be reviewed since this literature examines some important variables which are included in this quality of life study. Appendices F and G summarize the cardiovascular QOL studies and the family QOL studies respectively.

Four of the heart failure studies are randomized trials which are drug studies (Baligadoo et al., 1990; Guyatt et al., 1988; Kubo et al., 1992; Tandon et al., 1988). Although specific results of these studies are valuable, it is the symptomatology of heart failure that is important to this discussion of QOL. Tandon et al. (1988) reported that as sleeplessness and shortness of breath increased, performance on the exercise treadmill test decreased.

Similarly, Dracup, Walden, Stevenson, and Brecht (1992) studied 134 heart failure patients and found many suffered from shortness of breath, fatigue, and weakness. Their mean functional level for daily living was five metabolic equivalent units (METS). An individual functioning at five METS is able to perform only basic activities of daily living such as dressing and undressing or preparing a meal. In addition, heart failure patients described themselves as moderately to severely depressed. In a stepwise regression equation assessing psychosocial adjustment, depression accounted for 35% of the explained variance. This finding has significant implications for the future provision of psychosocial support for heart failure patients. No significant relationship was found between ejection fraction as a measure of cardiac function and quality of life measures. The authors used instruments with proven psychometric data. Although subjects were included from all four New York Heart Association functional classifications, the subjects were not separated for any of the analysis. It would have been interesting to compare psychosocial measures based on the level of functional classification.

Muirhead et al. (1992) examined quality of life and coping in patients awaiting cardiac transplantation. Using the Profile of Mood States, the Dyadic Adjustment Scale, the Derogatis Symptom Checklist, and the Lazarus Ways of Coping Checklist, the investigators examined the psychosocial correlates of quality of life in 41 patients waiting for a heart. Seventy-eight percent of those sampled reported they were in poor health. This was supported by high percentages of patients reporting fatigue, reduced physical strength, shortness of breath, fluid retention, and difficulty maintaining an erection. Most reported high marital satisfaction and stated that they were coping at least adequately. Interestingly, the mean quality of life reported on a 1 to 7 scale (1 = excellent QOL) was 4.2. Approximately one-third (34.1%) reported that their quality of life was poor and 26.8% reported that their quality of life was good. The other 45% were somewhere in the middle.

Mayou, Blackwood, Bryant, and Garnham (1991) found similar results to Dracup et al. (1992) and Muirhead et al. (1992). In addition, Mayou et al. found that heart failure patients were able to perform most activities as they did prior to their heart failure; however, the time spent doing those activities was significantly increased. This finding was uncovered via the qualitative portion of the study and has significant implications for heart failure QOL researchers. Most instruments simply ask the respondents' ability to perform certain activities. Thus, the instruments are not sensitive to the increased length of time needed by patients to perform activities or the distress this slower pace might cause. Indeed, some instruments may not be sensitive to the heart failure population at all for this reason.

Rector, Francis, and Cohn (1987) lend further support to the notion that objective physical measures do not necessarily accurately predict quality of life. Rector et al. found that perceived dysfunction and peak O_2 consumption were only moderately but significantly correlated in 45 heart failure patients. Thus, other subjective phenomena must also play a role in predicting quality of life.

Walden et al. (1989) compared the quality of life of 24 HT patients to 20 patients with end-stage heart failure who survived medical therapy for 6 months. One-year actuarial survival was 87% for the transplanted group and 76% for the end-stage heart failure group. The researchers found no significant differences between the groups in anxiety, depression, and hostility. There were no significant differences in psychosocial adjustment, with the exception of heart transplant patients having better levels of social function. Additionally, the heart transplant patients were able to achieve significantly higher METS on treadmill testing (7.3 vs. 5.9). Surprisingly, there were no significant differences in employment status between the end-stage heart failure group (25% working) and the transplant group (21% working). Since there was no difference in quality of life and only minimal difference in one-year survival, this data would seem to support maintaining stable end-stage heart failure patients on tailored medical therapy for as long as possible.

In summary, exercise tolerance, activity tolerance, dyspnea, fatigue, and psychological variables appear to be those most measured in the heart failure QOL literature. Objective physical measures are weakly related or not at all related to quality of life (Jessup & Brozena, 1988). In the Dracup et al. (1992) regression equation, depression appeared to be the major predictor for quality of life. The use of stepwise regression for a prediction equation highlights the lack of use of theory in QOL research. Ideally, theory should determine the order in which variables are entered into a regression equation. However, the findings of Dracup et al. do lend support to the need for psychosocial support in this population.

Two angina studies are included in this review, which are different in scope. Wiklund, Comerford, and Dimenas (1991) examined the relationship between exercise tolerance and quality of life in patients with angina. The second study involved a clinical trial examining the effect of transdermal glyceryl trinitrate on quality of life in angina patients (Fletcher, McLoone, & Pulpitt, 1988).

Wiklund et al. (1991) found no significant correlation between subjective indicators of well-being and workload measured by exercise tolerance testing in 50 angina patients. There was, however, a significant moderate correlation between psychological well-being and the severity of angina ($r = -.57$, $p < .0001$). In addition, there was a significant low-moderate negative correlation between treadmill time and depression ($r = -.36$, $p = .01$) meaning that as exercise tolerance (treadmill time) decreased, depression increased. Surprisingly, there was no significant relationship between life satisfaction and severity of angina. These results lend some support to the notion that quality of life is multi-factorial and is composed of both physical and psychological factors. Additionally, objective exercise tolerance testing was again not predictive of perceived QOL.

Fletcher et al. (1988) compared the effects of transdermal glyceryl trinitrate (Nitroglycerin patch) and placebo on the control of angina and quality of life. The investigators found that patients on transdermal glyceryl trinitrate had less angina and overall improvement in quality of life as measured by the Sickness Impact Profile. Interestingly, the greatest difference from placebo to the drug was an improvement in social interaction ($p < .01$) on active drug. This study was randomized, had a large sample size and utilized a cross-over design. The methods, data collection techniques and statistical tests were appropriate.

Nine studies were reviewed examining the effect of myocardial infarction on quality of life. Three of the studies examined the effect of post-MI cardiac rehabilitation on quality of life (Daumer & Miller, 1992; Oldridge et al., 1991; Packa et al., 1989). Three studies dealt with the psychosocial effects of myocardial infarction on the person's life (Hlatky et al., 1986; Wiklund, Sanne, Vedin, & Wilhelmsson, 1984; Mayou, Foster & Williamson, 1978b). One study examined time trade-offs in patients post-MI (Tsevat et al., 1991) and two were drug studies (Olsson, Lubsen, vanEs, & Rehnqvist,1986; Wiklund, Herlitz & Hjalmarson, 1989).

Daumer and Miller (1992) and Oldridge et al. (1991) examined the effect of cardiac rehabilitation on quality of life post-MI. Daumer and Miller (1992) utilized two groups of conveniently sampled post-MI patients. One group (N = 21) received formal outpatient rehabilitation. The second group (N = 26) received self-directed home rehabilitation based on instructions from the patient's physician. There were no significant differences between the groups in quality of life or psychosocial status. A concern with this study is that perhaps the instruments were not sensitive enough to detect subtle differences in physical function. This study also suffers from the biases introduced with convenience sampling and one-time cross-sectional designs.

Oldridge et al. (1991) randomized post-MI patients into a rehabilitation group, consisting of 8 weeks of exercise and relaxation training, and a conventional community care group. Data was collected at five different time points throughout the first year post-MI. At 8 weeks, the rehabilitation group had significantly better emotional scores, less anxiety, and better exercise tolerance over those in conventional community care. No significant differences were found between the groups at 1 year. Interestingly, the improvement in the intervention group ceased when the intervention stopped. At 12 months, there were no significant differences between the groups. There are several implications of this study. First, formal cardiac rehabilitation should be encouraged over a home prescription for exercise. Second, the usual 8 week program may not be sufficient to develop long-term habits. Third, exercise needs to be tested further as an intervention to improve overall quality of life.

Packa et al. (1989) assessed quality of life in 51 elderly patients with coronary artery disease undergoing cardiac rehabilitation. The subjects rated their quality of life as an 8 on a 10-point Cantril Self-Anchoring Scale at the time of the interview. Pre-cardiac rehabilitation, they rated their quality of life as a 5 and they expected it to be a 9 upon completion of the program. There are several weaknesses of this study. First, the pre- and post-rehabilitation data are retrospective and projected. The study would have been stronger if the authors collected the actual data pre- and post-rehabilitation. In addition, subjects were enrolled in the rehabilitation program from one to 12 months. No analysis was done to assess for differences in QOL across the year. Quality of life may have improved over the course of the year because of improved exercise capacity or possibly because of increased socialization among participants.

Hlatky et al. (1986) examined predictors of return to work in 814 men with coronary artery disease. The major predictor of work disability was low educational level, followed by a history of MI, depression, and hypochondriasis. Perhaps the type of work or employment setting may have had something to do with return to work, but this was not measured. Additionally, the way disability benefits are allocated may also affect work disability. Such studies have definite policy implications in the areas of job retraining and disability benefit allocation. It would have been interesting to note how many subjects were "electively" disabled vs. medically disabled.

Wiklund et al. (1984) and Mayou et al. (1978b) reported similar results in their studies. Both found that patients still had some cardiovascular and psychological symptoms and increased stress one year post-MI. The Wiklund et al. group reported that 62% of their sample were satisfied with their life 1 year after MI and 9% were dissatisfied. Life satisfaction was not addressed by Mayou et al. Both studies were longitudinal and followed the patients for 1 year. Both groups utilized convenience sampling methods for their MI patients although the Wiklund group used a random sample of control subjects as a reference group. Neither group used tested instruments or reported psychometric data on their instruments. Both studies support Julian's (1987) contention that physicians need to address the problems of anxiety and stress post-MI.

In summary, quality of life research in MI and angina patients focused on exercise tolerance, symptoms (primarily angina), return to work, and psychological variables. Most patients continued to have cardiac symptoms post-MI and many suffered from increased stress. Cardiac rehabilitation studies need to continue with longer intervention periods and data collection periods. It would be interesting to note if long-term benefits of cardiac rehabilitation would continue beyond the intervention phase if the intervention last for a longer time.

Family Quality of Life

Little attention has been focused on the quality of life of spouses or other family members of patients with acute or chronic illness. Only six studies were found that specifically measured quality of life in spouses of ill patients (Artinian & Hayes, 1992; Ebbesen et al., 1990; Leavitt, 1990; Mathieson et al., 1991; Sexton & Munro, 1985; Voepel-Lewis et al., 1990). Other studies cited in this review address a variety of other subjective measures frequently used in research to address quality of life issues.

Quality of life was measured in a variety of ways by the above authors. Artinian and Hayes (1992) measured quality of life using the Ferrans and Powers Quality of Life Index in 39 spouses of coronary artery bypass patients one year after surgery. Using stepwise regression, the authors developed a prediction equation for quality of life. The spouse's ailments, perception of his/her own health, and affirmation support contributed significantly to the prediction of quality of life. However, the authors never indicated the total amount of variance accounted for by the regression equation. In addition, stepwise regression is an atheoretical statistical technique that needs to be questioned whenever it is used. Other variables that had significant bivariate correlations with quality of life but were not significant predictors of quality of life in the regression equation were social support, income, and the perception of their partner's health.

The purpose of Ebbesen et al.'s (1990) study was to validate a new instrument developed by the authors, the Quality of Life Questionnaire for Cardiac Spouses. Acceptable correlations were obtained between the subscales of the Quality of Life Questionnaire for Cardiac Spouses and the Rand Quality of Well-Being Scale ($r \geq .50$) meaning that concurrent validity of the instrument was supported. Very low correlations were obtained between the physical subscale of the Quality of Life Questionnaire for Cardiac Spouses and the Katz Instrumental Activity of Daily Living Index, and the self-anchoring QOL scale for the emotional and physical subscales. Given the level of the correlations, the Quality of Life Questionnaire for Cardiac Spouses needs further validity testing and possible revision.

Leavitt (1990) used qualitative methods to assess quality of life through a semi-structured interview. Family partners of 21 vascular surgery patients reported lower quality of life than their patient partners 3 months after surgery. Mathieson et al. (1991) measured quality of life via a 0-10 point rating of life happiness in 30 spouses of laryngectomy patients. Controlling for age, gender, and medical information about the patient, lifestyle changes accounted for a significant amount of variance in QOL.

Sexton and Munro (1985) used the Neugarten, Havinghurst and Tobin Life Satisfaction Index-A to measure quality of life in 46 women whose husbands had COPD and 30 women with healthy husbands. Using stepwise regression, subjective stress, money, the diagnosis of COPD, and whether or not the spouse worked accounted for 49% of the variance in QOL. Once again, stepwise regression was used; thus there was no theoretical basis for the entry of variables into the equation.

Finally, Voepel-Lewis et al. (1990) measured quality of life in 50 pre- and post-renal transplant family members via a 7-point likert rating scale. The scale used the following anchors: terrible, unhappy, mostly dissatisfied, mixed, mostly satisfied, pleased, and delighted. The words used in the scale could cause some confusion since the authors combined happiness and satisfaction because happiness and satisfaction describe different affective states. The authors found stress and coping, as measured by the Kidney Transplant Questionnaire (KTQ), accounted for 19% of QOL variance pre-renal transplant and 25% post-renal transplant in predicting quality of life.

The impact of stress on quality of life appears to be a major variable in the spousal literature. Artinian (1991) reported persistent stress, as measured by Artinian's Spouse Stressor Scale, in 86 spouses 6 weeks after coronary artery bypass graft surgery. Mathieson et al. (1991) reported greater tension, as measured by the Profile of Mood States, in 30 laryngectomy spouses as compared to the patients. Bohachick and Anton (1990) assessed 90 couples; one of each pair had severe cardiomyopathy. They found that spouses had more psychological distress and were significantly less well adjusted than their patient partners as measured by the Psychosocial Adjustment to Illness Scale. Buse and Pieper (1990) reported high levels of stress, as measured by the Subjective Stress Scale, in 30 spouses of patients awaiting heart transplantation. It is important to note that the spouses sampled by Buse and Pieper reported pre-transplant data retrospectively.

Ebbesen et al. (1990) queried 42 spouses of patients who had recently had a myocardial infarction (MI). They found that the spouses have typically visited their own physician with complaints of headaches, high blood pressure, and nonspecific chest pain within the 8 weeks after the patient's MI. Such symptoms are typically associated with increased stress. Sexton and Munro (1985) reported significantly higher stress levels in 46 wives of COPD patients as compared to 30 wives whose husbands did not have a chronic illness. In fact, subjective stress, as measured by the Subjective Stress Scale, accounted for 28% of the variance in life satisfaction. Gilliss (1984) reported significantly higher subjective stress in 41 spouses of CABG patients than in the patients themselves. Stress was measured by a semi-structured interview and the Impact of Event Scale. Finally, Stern and Pascale (1979) reported high anxiety levels, as measured by the Taylor Manifest Anxiety Scale, in 38 spouses of MI patients.

In conclusion, stress is an important variable in assessing the quality of life of spouses of patients with serious acute or chronic illness. It also appears, by virtue of the instruments used, that stress was measured as both general and as specifically related to the patient's illness.

Coping is also measured in several of the spousal studies (Artinian, 1991; Leavitt, 1990; Miller & Wikoff, 1989; Nolan et al., 1992; Voepel-Lewis et al., 1990). Using the Jalowiec Coping Scale, Miller and Wikoff (1989) reported that the use of emotive coping methods was negatively correlated with overall marital quality in 40 patients and spouses 3 months after the patient's first MI.

Mishel and Murdaugh (1987) interviewed 20 family members of HT patients. Family members were at different stages of the heart transplant process. Seven family members were pre-transplant; 8 had recently transplanted family members; and 5 were post-transplant. The authors found that coping behaviors such as trading places and negotiation were used by these families. This study used grounded theory to examine family members of cardiac transplant patients before transplant, immediately after transplant, and long-term after transplant. No specific time frames were offered in regards to the patient's time on the waiting list or time post-operatively.

Although Mishel and Murdaugh provide a plausible explanation of families' coping behavior at different time points, the study is flawed in many ways. First, the family members studied were those who participated in support group sessions. Those who participate in support groups may be inherently different than those who choose not to participate. Second, the 1.5 hour support group sessions were not tape-recorded; instead, the investigators dictated information on audiotape after the support group meetings ended. Data recorded in this manner is both biased and incomplete. Third, in order to assess the credibility of the data, the investigators checked the data with other transplant team members. The data should have been checked and validated with the family members of the patients participating in the support groups. Lastly, some of their proposed theoretical subheadings do not clearly describe what type of activity occurs within that category. For example, one does not readily know what type of activities are taking place within the "smelling the roses versus life as it used to be" stage as opposed to the "back to normal versus recognizing risks" stage.

It seems essential to include a measure of coping when stress is being addressed. By including a measure of coping, the researcher can understand how spouses manage stress, constructively or not, and plan interventions appropriately. In addition, it seems reasonable to surmise that the better or worse people cope with stress or adversity would positively or negatively influence their overall perception of quality of life.

Measures of social support, family support, and coping resources tend to be cited in the family literature as being important. Artinian (1991), Gilliss et al., (1990), and Leavitt (1990) utilized some measure of social support or family resources. Artinian used the Norbeck Social Support Index; and both Gilliss et al. and Leavitt utilized the Family Inventory of Resources for Management. Artinian (1991) reported that the spouses of CABG patients had high levels of social support during the immediate post-operative period and 6 weeks later. Gilliss et al. (1990) reported that family resources decreased for spouses over the course of 3 to 6 months after CABG surgery. Leavitt (1990) reported that family members were reluctant to ask for help during the first 3 months after vascular surgery whereas the patients felt entitled to ask for help.

In assessing this body of literature as the beginnings of studying quality of life in the family of patients awaiting HT, it seems as though the psychological and social domains of the concept are adequately addressed, although in a limited number of studies. One striking missing variable, seemingly essential when studying quality of life in _patients_, is the physical domain. Only two of the studies (Artinian & Hayes, 1992; Ebbesen et al., 1990) measured a physical variable in their research. This is certainly not in keeping with current quality of life thinking. Additionally, this makes the unwritten assumption that family members are healthy; thus, measuring a physical aspect of quality of life will contribute little in assessing their quality of life. It would be difficult to develop a rating tool that would assess all of the possible physical problems that family members may have. An alternative approach would be to include a one-item rating scale asking family members to rate the level of their health. This was the approach Artinian and Hayes (1992) used.

Secondly, some authors make the assumption that a spouse's quality of life revolves around the condition of the patient. This assumption is implied by the authors by primarily measuring stressors associated with the patient's illness (Buse & Pieper, 1990; Sexton & Munro, 1985; Voepel-Lewis et al., 1990). Others make this assumption by not including more global measures of family function. For example, Mathieson et al. (1991) measured body image, relationships, restrictions on the patient, emotions, and overall quality of life. There is no measure of other family stressors such as caring for a young child or disabled parent. There is also no measure used of resources available to the family for coping with their stress. Many stressors with adequate resources may not impact on quality of life as much as many stressors and no resources. Thus, only a very limited view of family quality of life is addressed by these studies.

After examining the family literature carefully, several variables appeared to be important in predicting quality of life in spouses of patients with various illness. Stress and/or coping were measured in some form in all of the family studies reviewed. Additionally, a measure of support or coping resources were cited by four authors (Artinian, 1991; Bohachick & Anton, 1990; Gilliss et al., 1990; Leavitt, 1990). In addition, two authors developed regression equations for quality of life in which three additional variables contributed to the prediction of the concept. These variables were ailments, perception of the spouse's health (Artinian & Hayes, 1992), and whether or not the spouse was employed (Sexton & Munro, 1985).

Gaps Identified in the Literature

After this discussion of quality of life, some consistent gaps in this literature can be identified. First, there is no commonly accepted definition for quality of life. Definitions of quality of life seem to cluster under satisfaction or happiness, the achievement of goals, general well-being or physical functioning. Lack of definitional clarity leads to measurement confusion. One cannot develop precise widely accepted instruments without a definitive, widely accepted, expression of what one is measuring. With conceptual clarity being such a problem, theory building is nearly impossible.

There seems to be consensus that there are three consistent domains that should be measured in any quality of life study: physical, psychological, and social. In addition, a disease-specific domain should be included to capture those findings germane to individual disease states. There is no consensus however on what specific variables should be measured within each domain. So essentially, a researcher could justify including any variable in a QOL study as long as it had something to do with a physical, psychological or social domain. This problem highlights the need for the adoption of a "gold standard" measurement tool.

Model building or theory building cannot be accomplished when the building blocks or variables are continuously changing, so until variables become more stable, model development will be difficult. In addition, the current models are primarily unidirectional and do not allow for feedback to the original variables. Some authors simply list variables under the accepted domain headings of physical function, psychological function and social/family function and call this a model. There is no consideration given to how the variables interact and influence each other and ultimately the overall perception of quality of life. Thus, theory development is a major gap in the quality of life literature.

There are very few family QOL studies reported in the literature. Researchers and health care providers are beginning to recognize the importance of family members in health care. They are recognized because of the potential benefit they can offer patients in recovery but also as potential patients themselves. The research presented in this review confirms that family members experience high stress levels and illness themselves following the illness of a family member. Thus, families need to be incorporated into quality of life research.

Lastly, long-term follow-up in QOL research is problematic. Subjects may be followed for six months to one year but very few studies extend the follow-up any further. This short-term perspective may provide a very biased view of quality of life for certain disease entities.

Some of the gaps in the literature were addressed by this dissertation. Although the amount of QOL literature is vast, more research is needed focusing on quality of life for families. This study addressed that need. The sample sizes need to be determined by some systematic method such as power analysis. Sample sizes of ten subjects with six variables are unacceptable. Thus, sample size for this dissertation was determined by power analysis.

A few "gold standard" measures need to be adopted. This would assure that several of the same variables are measured in all QOL studies so that comparisons could be made across disease entities and cultures. In addition, the use of meta-analysis across samples would be made easier thereby providing larger data bases from which to draw conclusions. The Ferrans and Powers Quality of Life Index (1984) has been used across several populations and may indeed become a "gold standard" instrument for QOL research.

A concerted effort needs to be made towards theory development in QOL research and antecedents, mediating variables, and consequences need to be clearly delineated. Models then need to be tested using causal modeling techniques such as path analysis or LISREL. Theories can then be improved upon and eventually tested in clinical practice.

Realistically, it would be difficult to design a perfect quality of life study within the time constraints of a dissertation. This study contained some of the weaknesses criticized by this investigator in prior research. The sample was cross-sectional and not randomized. Spouses were queried only once; thus, this study was not longitudinal. Although weaknesses exist in this proposed methodology, this study did provide needed information to the heart transplant community. In addition, it is hoped that this research will serve as a catalyst for future research.

Preliminary Study

Prior to the dissertation research, a qualitative pilot study was conducted by the investigator with five female spouses of HT candidates. Spouses were asked to describe the experience of having their spouse on the HT waiting list and how this impacted on their own lives. Additionally, spouses were asked: (1) to identify stressors they experienced while their partner was awaiting heart transplantation; (2) to describe how they were coping with their spouse waiting for heart transplantation; and (3) to describe what impact, if any, waiting for heart transplantation had on their marriage. Data was analyzed using thematic analysis.

All 5 spouses reported that the transplant process had adversely affected their lives. All reported being under a tremendous amount of stress and being frightened that their spouse might not survive to transplant. Two expressed difficulty in assuming added responsibilities such as day-to-day household chores and financial burden. All expressed some difficulty sleeping since their spouse was listed for transplant. Two reported sexual difficulties since their spouse had become ill. Three coped with the illness by "turning to God," while two others reported that keeping busy was the key to surviving this process. One spouse reported that her marriage improved during the transplant process because her husband faced an alcohol problem and stopped drinking. Three reported no change in their marriages and one reported that her marriage had deteriorated since her husband became ill. One spouse, reporting no change in her marriage, did state that her husband was no longer interested in how she was feeling. She stated, "he doesn't sympathize when I'm tired or in need of a boost...If I say I'm tired, he'll say, well how would you like to have a bad heart. I have to protect him so I just don't tell him things anymore...I don't have an out no more. There's no one there for me."

Data from this pilot study helped to develop items for the Spouse Transplant Stressor Scale used in this dissertation study, and to validate that important areas of concern for spouses of HT candidates were being addressed in the dissertation.

CHAPTER III

METHODOLOGY

Purpose of the Study

The purpose of this study was to identify predictors of quality of life for spouses of heart transplant (HT) candidates. Specific aims for this project were:

1. Identify stressors experienced by HT spouses during the wait for HT.
2. Identify coping mechanisms, coping ability, and family resources used by spouses of HT candidates to handle stress during the HT waiting period.
3. Assess the impact of the HT experience on spouses of HT candidates during the wait for a heart donor.
4. Assess levels of life satisfaction and perceived overall QOL for spouses of HT candidates during the wait for HT.
5. Determine differences in stress, coping, family resources, and QOL based on gender, work status, the patient's health status, and the impact of the transplant experience.
6. Determine the relationships between selected demographic and health-related variables, stress, coping, family resources, transplant impact, and QOL.

7. Determine predictors of quality of life for spouses of HT candidates.

Research Design

A cross-sectional, correlational design using survey research methods was utilized. The Lazarus and Folkman Stress and Coping model, as described in the previous chapter, was used as the conceptual framework for this study.

Sample

This non-random sample consisted of 85 spouses of patients awaiting cardiac transplant at three sites: Loyola University Medical Center (LUMC), Hines Veterans Affairs Hospital (HVAH), and the University of Alabama (Birmingham) Medical Center (UAB). LUMC and HVAH are adjacent medical centers with a combined heart transplant program. The UAB site was specifically chosen: (1) because the investigator's dissertation chair has an ongoing National Institutes of Health (NIH) heart transplant quality of life grant at LUMC and UAB; and (2) to obtain the necessary sample size quickly. Access to spouses was not problematic since the investigator was the heart transplant coordinator at HVAH, had access to and permission to solicit subjects from LUMC, and had a commitment of cooperation from the UAB NIH study site coordinator. Forty-one subjects (48.2%) were spouses of patients waiting at LUMC, 13 at HVAH (15.3%), and 31 from UAB (36.5%).

In order to increase the potential pool of subjects within the time constraints of a dissertation, all spouses were sampled, regardless of how long the patient had been on the heart transplant waiting list. Sample eligibility criteria were as follows:

1. The subject must have been a spouse of a patient listed for heart transplantation at LUMC, HVAH, or UAB at the time of the study.
2. The subject must have been 18 years or older.
3. The patient partner must have been actively awaiting heart transplantation (he/she could not be on hold for transplant); and
4. The subject must have been able to read and write English.

The response rate for this study was 80%. Two booklets were completed by the spouse after the patient was transplanted; therefore these booklets were not used in the analysis. Reasons for not participating were as follows: the patient was transplanted before the booklet was completed and returned (N = 7, 32%); the patient died before the booklet was completed (N = 4, 18%); the spouse refused to participate (N = 4, 18%); the spouse did not return the booklet after repeated mailings (N = 4, 18%); or the patient was taken off the list or put on hold before the booklet was completed (N = 3, 13.6%).

Power analysis, using the Borenstein and Cohen (1988) statistical program, indicated that more than sufficient power was obtained with the sample size of 85 subjects for a regression analysis of eight independent variables and one dependent variable. A power of 1.00 was obtained with an alpha of .05, a sample size of 85, and the large effect size found ($f^2 = 2.45$).

Of note, the power analysis proposed for this dissertation was run with nine independent variables and one dependent variable (power = .75, alpha = .05, $f^2 = .15$, N = 104). Three variables were dropped from the equation because they were not significant when force entered into the regression equation first (duration of time the patient was on the HT waiting list, the spouse's perception of the patient's health, and the spouse's employment status). Two variables were then added to the equation bringing the number of independent variables in the model to eight. The patient's objective health status (ICU vs. not ICU) was substituted for the spouse's perception of the patient's health and the spouse's overall level of stress was added to the stress appraisal portion of the model.

The mean age of the subjects was 51.45 years (SD = 8.55, range = 27-64). The mean age of the heart transplant patients was 53.88 years (SD = 8.71, range = 24-67). The spouse sample was primarily female (90.5%), caucasian (94.1%), married for a long time ($\overline{X}$ =

26.24 years), and had 2.68 children. Seventy-five percent of the subjects were in their first marriage (N = 64). Sixty-seven percent of the sample (N = 57) had no dependent children at this time. Seven percent of the subjects (N = 6) had other dependent relatives living with them.

The subjects were well educated, with 51% completing one year of college or more ($\overline{X}$ level of education = 13.20 years, SD = 2.22, obtained range = 7-20 years). The family income ranged from below $10,000/year to $150,000/year or more; the median income was $40,000/year. Four respondents (4.7%) did not answer the income question.

Seventy-six percent of the sample (N = 65) worked outside the home. The number of hours worked ranged from 0 to 55 ($\overline{X}$ number of hours worked = 27.59). Subjects' occupations were classified according to Hollingshead's Occupational Scale (Hollingshead & Redlich, 1958). Results were: 1) major professional, N = 1 (1.5%); 2) business managers, proprietors of medium-sized businesses, and lesser professionals, N = 13 (20.3%); 3) administrative personnel, owners of small businesses, and minor professionals, N = 20 (N = 31.2%); 4) clerical/sales workers, technicians, and owners of small businesses, N = 13 (20.3%); 5) skilled manual employees, N = 5 (7.8%); 6) machine operators and semiskilled employees, N = 11 (17.1%); and 7) unskilled employees, N = 2 (3.1%).

Fifty-one subjects (60%) listed specific health problems that they were having at the time of the study. The five top health problems listed were: 1) high blood pressure, N = 20 (39.2%); 2) arthritis, N = 12 (23.5%); 3) nerves, anxiety, depression, N = 11 (21.6%); 4) heart problems, N = 8 (15.7%); and 5) bowel problems, N = 7 (13.7%). At the time of this study, 12 of the subjects' spouses (14.1%) were awaiting HT in an intensive care unit (ICU), one on a general floor (1.2%), and 72 at home (84.7%).

Instruments

The main study variables for this dissertation were classified under the four main headings in Lazarus' model: stress, appraisal, coping and adaptational outcome. A stressor was defined as a stimulus, such as individual illness or an illness in the family that generates an appraisal response by the individual. Potential stressors measured in this study were: perceived health of the patient, perceived health of the spouse, employment status of the spouse, and duration of time the patient had been waiting for a heart. Appraisal was defined as a judgment or evaluation that an individual makes about a specific event, encounter, or stressor. Appraisal variables were: spouse stressors, the overall level of stress and the impact of transplantation on the spouse's life.

Coping was defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). The coping variables were: types of coping methods used (confrontive, supportant, self-reliant, optimistic, palliative, evasive, fatalistic, and emotive) and the effectiveness of them in coping with having a spouse waiting for a heart transplant, overall coping ability, and family resources available for coping. Quality of life was defined as "a person's sense of well-being that stems from satisfaction or dissatisfaction with areas of life that are important to him/her" (Ferrans, 1990, p. 15). Quality of life was the dependent variable for this dissertation.

The instruments that were used to measure the above variables were: the Spouse Transplant Stressor Scale, the Family Inventory of Resources for Management, the Jalowiec Coping Scale, the Ferrans and Powers Quality of Life Index, a six-item Rating Form, and a Demographic Data Sheet. The instruments used are in Appendix H. Permission to use the Family Inventory of Resources for Management, the Jalowiec Coping Scale, and the Ferrans and Powers Quality of Life Index was granted by the authors of those instruments (see Appendix I).

Spouse Transplant Stressor Scale (STSS)

The STSS was developed by the investigator for this study. Items were generated from a pilot study, the investigator's clinical experience, a review of the literature, and five existing stressor scales: the Family Perception of the Transplant Experience Scale (Nolan et al., 1992), the Family Inventory of Life Events (McCubbin, Patterson & Wilson, 1981), the Heart Transplant Stressor Scale (Jalowiec, Grady, & Grusk, 1988), the Perception of Heart Transplantation Questionnaire (Buse & Pieper, 1990), and the Spouse Stressor Scale (Artinian, 1988). The STSS has 61 items rated on a likert scale from 0 to 3 (0 = not stressful, 3 = very stressful). Items include both stressors related to the transplant experience (45 items, 74%) and major stressors experienced by families but not necessarily related to the transplant.

Content validity was verified by two HT coordinators and a HT psychologist. The experts were asked to review the tool for comprehensiveness, meaningfulness, and clarity of wording. The original instrument had 36 items. One content expert suggested adding items to capture more transplant stressors that spouses of HT candidates might experience so 14 items were added to accomplish this. Another content expert suggested expanding certain items into more specific questions. For example, an item labeled my job was expanded to: losing my job, not being able to do my job as well as before because of my spouse's illness, and having to take time from my job because of my spouse's illness. The overall item, my job, was eliminated. Similarly, one proposed question on sexual activity was expanded to four questions. Some ambiguous items in the instrument were clarified. All three content experts agreed that the final instrument clearly and sufficiently addressed the stressors experienced by heart transplant spouses.

In addition, the instrument was given to two spouses of heart transplant patients for content validity assessment. The spouses were asked to look for unclear wording and to check if all stressors that they had experienced, or wives of other heart transplant patients had experienced, were addressed in the instrument. The spouses reported that the wording was clear and that all of the stressors they, and others like them, had experienced were addressed.

Subscales for the STSS were determined via a thematic clustering of items. Two HT coordinators, a HT psychologist, and a HT quality of life researcher reviewed the items for appropriate classification into the subscales set up by the investigator. As a result, several items were re-classified based on this feedback. There was a suggestion by one reviewer that the transplant stressor subscale might be broken down into affective and cognitive transplant stressor scales. This was not done due to the small number of items that would result for each subscale.

The sample size was not large enough to perform an exploratory factor analysis to empirically test for subscale classification.

The four STSS subscales delineated were: transplant stressors, socioeconomic stressors, responsibility stressors, and stressors related to self (see Appendix J). Homogeneity reliabilities for the STSS were (N = 85): total scale, .96; transplant stressor subscale, .90; socioeconomic stressor subscale, .86; responsibility stressor subscale, .79; and stressors related to self subscale, .92. These coefficient alphas support homogeneity reliability of the total scale and subscales. Of note, a singular matrix (determinant = 0) was obtained for the total scale results. This indicates that there was some redundancy among the items. Singular matrices were not obtained on any of the subscales.

Concurrent validity of the tool was assessed by correlating the score on the STSS with the one-item overall stress rating from the Rating Form. A significant correlation between the STSS total score and the one-item stress rating supported concurrent validity ($r = .62$, $p = .000$, $N = 85$).

Scoring for the STSS was performed by adding the ratings for all of the items to compute a total score. The possible range of scores was 0-183. A high score on the STSS equaled a high level of stress during the HT waiting period. The total score was used for the regression analysis.

Family Inventory of Resources for Management (FIRM)

The FIRM (McCubbin, Comeau, & Harkins, 1981) assesses family resources based on the assumption that the more resources a family has, the better they will be able to manage stress and crisis. The FIRM is a likert scale consisting of 69 items divided into six subscales: esteem and communication, mastery and health, extended family social support, financial well-being, sources of financial support, and social desirability. Responses range from 0-3 (0 = describes our family not at all, 3 = describes our family very well). Some examples of resources measured are: money available for small purchases, control, cooperation and responsibilities.

The FIRM was scored by adding the numbers circled for the first four subscales (i.e., esteem and communication, mastery and health, extended family social support, and financial well-being). Thirty items were worded negatively; therefore the scores on these items needed to be reversed before the scores were totaled. A total score of 93-129 indicates a moderate level of family resources. A score below 93 indicates a lack of or depletion of resources, and a score above 129 indicates better-than-average resources that a family can call upon (McCubbin & Comeau, 1987).

Validity and reliability information is provided for the first four subscales. McCubbin and Comeau (1987) state that the other two subscales, sources of financial support and social desirability, provide useful additional information but are not considered major dimensions of the FIRM. The subscales were determined via factor analysis. Factor loadings for the first four subscales ranged from .71 to .24 (N = 322) (McCubbin & Comeau, 1987). A factor loading of .30 is generally accepted as the minimum cutoff for significance (Nunnally, 1978). Only five items fell below the .30 cutoff, indicating that most items loaded significantly on a factor.

Internal consistency reliabilities for the FIRM were (N = 322): total scale, .89; esteem/communication, .85; mastery/health, .85; extended family social support, .62; and financial well-being, .85 (McCubbin & Comeau, 1987). These coefficient alphas support homogeneity reliability, with the exception of the extended family social support subscale which is slightly lower than the acceptable norm of .70 (Nunnally, 1978). For this study, the internal consistency reliabilities were (N = 85): total scale, .91; esteem/communication, .89; mastery/health, .88; extended family social support, .75; and financial well-being, .85. These coefficient alphas further support homogeneity reliability of the FIRM. Of note, a singular matrix was obtained for the total FIRM scale. No singular matrices were obtained for the subscale reliabilities.

Concurrent validity was assessed by correlating scores on the FIRM with scores on the Family Environment Scale (FES) (N = 322 families). The FES measures family relationships and characteristics. As expected, a significant positive correlation existed between the cohesion, expressiveness and organizational scales on the FES and the four FIRM scales (McCubbin & Comeau, 1987). A significant negative correlation was found between the FES conflict scale and the four FIRM scales, meaning that as conflict increased, family resources expectedly decreased.

Concurrent validity was also supported by logical correlations from this study. The total FIRM score was significantly and positively correlated with the overall coping ability rating ($r = .40$, $p = .000$) and the adjusted coping effectiveness score from the Jalowiec Coping Scale ($r = .48$, $p = .000$). In addition, the total FIRM score was significantly and negatively correlated with the overall level of stress rating ($r = -.34$, $p = .001$) and the total stressor score ($r = -.41$, $p = .000$). This means that as more family resources were available for coping, overall coping ability and coping effectiveness were better. Conversely, as less family resources were available for coping, the overall level of stress and the stressor score increased. Thus, concurrent validity was further supported for the FIRM.

Jalowiec Coping Scale (JCS)

The 1987 version of the JCS was used to assess coping behaviors for this study (Jalowiec, 1987a). The JCS has 60 items for which the subject answers on a likert scale how often the coping method was used and how helpful the coping method was (0 = never used/not helpful, 3 = often used/very helpful) in coping with the stress of having his/her spouse waiting for a heart transplant. The JCS has eight subscales: confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportant, and self-reliant coping. The subscales were determined by identifying common themes shared by particular theoretical clustering among the items (Jalowiec, 1987b).

The JCS overall adjusted coping effectiveness score was used for the multiple regression equation. The raw use and adjusted effectiveness scores were used for the eight subscales for correlational analysis. The adjusted effectiveness scores were computed by dividing the effectiveness scores for the total scale and for each subscale by the total number of coping methods used for the subscale and total scale. Persons scoring highest were those who report the highest use of the coping style and find it highly effective for them. Low scores indicate least use and effectiveness of the coping style.

Jalowiec (1991) summarizes psychometrics from 12 studies (N = 744). Cronbach alphas ranged from .64-.97 for total use and from .84-.96 for total effectiveness. Mean subscale alphas ranged from .48-.80 for use, and from .47-.80 for effectiveness. Test-retest reliability from HT candidates was stable at a 3-month interval with significant ($p < .002$) retest correlations of: total use = .72, total effectiveness = .65, coping use subscales = .53-.69, and coping effectiveness subscales = .27-.65 (Grady & Jalowiec, 1992).

Internal consistency reliabilities for the present study were: total use, .90; total effectiveness, .92; evasive use, .80; evasive effectiveness, .72; confrontive use, .79; confrontive effectiveness, .85; optimistic use, .75; optimistic effectiveness, .77; self-reliant use, .69; self-reliant effectiveness, .69; fatalistic use, .64; fatalistic effectiveness, .55; emotive use, .62; emotive effectiveness, .41; supportant use, .61; supportant effectiveness, .66; palliative use, .42; palliative effectiveness, .52. The above Cronbach alpha coefficients generally support internal consistency. The self-reliant use and effectiveness, fatalistic use and effectiveness, emotive use, and supportant use and effectiveness subscales fall slightly below the accepted norm of .70 (Nunnally, 1978). The emotive effectiveness and palliative use and effectiveness subscales fall below the accepted norm. The palliative use and effectiveness subscale reliabilities may be low because the palliative subscale contains both positive and negative coping strategies. "However, Billings and Moos (1981) cautioned that typical homogeneity estimates may have limited value in assessing coping measures since an upper limit may be placed on the coefficient because deployment of certain coping strategies may preclude the use of others" thereby resulting in many zero values (cited in Jalowiec, Murphy, & Powers, 1984, p. 158). These Cronbach alphas should not be problematic, however, since these subscales were not used in the regression equation.

Construct validity of the eight JCS subscales was supported by a panel of 25 stress and coping experts. The experts were asked to classify each of the items on the scale into the eight subscales based on definitions provided. The percent of agreement of the stress and coping experts with Jalowiec's classifications was as follows: supportant 94%, confrontive 86%, evasive 85%, palliative 76%, optimistic 72%, fatalistic 67%, self-reliant 66%, and emotive 54% (Jalowiec, 1991). Content validity was supported by the broad literature base used to generate items, the use of a large number of items to tap the conceptual domain of coping, and the inclusion of diverse types of coping behaviors (Jalowiec, 1991). Predictive validity testing showed that heart transplant patients who used less desirable coping methods (emotive, fatalistic, evasive) rated their stress higher, their health worse, and their life satisfaction and quality of life lower, and they also felt that they were coping poorly (Grady & Jalowiec, 1992; Jalowiec, 1991).

Concurrent validity for the JCS was supported by this study in that spouses who used less effective coping strategies rated their overall level of stress higher ($r = -.35$, $p = .001$) and had a higher total stressor score ($r = -.30$, $p = .004$). Conversely, those who used more effective coping strategies rated their overall ability to cope as better ($r = .36$, $p = .001$) and had more family resources available for coping ($r = .48$, $p = .000$).

In summary, a vast amount of validity and reliability data on the JCS has been accumulated and concisely summarized by Jalowiec (1991) and Grady and Jalowiec (1992). Reliability results are highly significant, indicating good reliability of the instrument. Construct, content, and predictive validity all indicate good support for the validity of the tool.

Quality of Life Index (QLI)

The QLI (Ferrans & Powers, 1984) is a generic quality of life instrument which assesses satisfaction with and importance of various areas of life. Satisfaction and importance are both assessed because satisfaction with areas of most importance influence quality of life more than areas of little importance to the individual. The QLI has 34 satisfaction items and 34 corresponding importance items. The first 34 items on the tool ask how satisfied the individual is with an area and the second set of 34 items asks how important these same areas are to the person. Subjects respond to the items on a 6-point likert scale ranging from (1) very dissatisfied to (6) very satisfied in the satisfaction section and (1) very unimportant to (6) very important for the importance section. There is no neutral middle response. The four subscales are: health and functioning, socioeconomic, psychological/spiritual, and family. Subscales were determined by factor analysis (Ferrans, 1990).

Based on instructions from the author of the tool, the instrument was scored by zeroing the satisfaction scale, adding 15 to that number, and then multiplying the adjusted satisfaction score and its paired importance response. This type of adjustment and weighting of scores was necessary to yield the highest scores for areas of highest satisfaction/ highest importance and the lowest scores for areas of lowest satisfaction/highest importance. Areas of lowest importance produce middle range scores.

The quality of life score used in the regression analysis was the total QLI score added to the one-item quality of life score on the rating form. Since the QLI score can range from 1-30 and the quality of life rating can range from 1-10, z-scores were used to obtain the composite score.

Reported Cronbach alphas for the QLI were good: total score, .93; health and functioning, .87; socioeconomic, .82; psychological/spiritual, .90; and family, .77 (Ferrans & Powers, 1985). Homogeneity reliability results for this study were as follows: total QLI score, .95; health and functioning, .89; socioeconomic, .83; psychological/spiritual, .91; and family, .50. With the exception of the family subscale, the above Cronbach alphas support internal consistency. Since the family subscale was not used in the regression equation, a low alpha was not problematic.

Test-retest reliability correlations were reported as .87 for 88 graduate students with a 2-week interval, and .81 for 39 dialysis patients with a 1-month interval (Ferrans & Powers, 1985). Concurrent validity was supported by correlating the QLI score with a single item on life satisfaction; correlations of .80 (Ferrans, 1990), .77 (Ferrans & Powers, 1985), and .89 (Hicks, Larson, & Ferrans, 1992) were obtained. To test construct validity, Ferrans (1990) used the known groups method to compare mean scores on pain, depression, and coping with the QLI scores. Subjects who had less pain, less depression, and better coping had significantly better quality of life ($p \leq .002$).

Rating Question Form

Six one-item rating questions were used to assess the following: overall level of stress (very little to very much), overall coping ability (very poorly to very well), perceived health of the spouse (very poor to very good), perceived health of the patient (very poor to very good), overall quality of life (very poor to very good), and the impact of the transplant wait on the spouse's life (very negative impact to very positive impact). The first five questions were in a likert format ranging from 1 to 10. The impact question responses ranged from -5 (very negative impact) to +5 (very positive impact). A rating of 0 at the center of the scale denoted no impact.

Demographic Information Form

Demographic information, such as age, gender, educational background, income, number of hours worked, occupation, duration of the wait for transplant, marriage length and number of dependent children were collected to provide descriptive information about the sample.

Procedure

LUMC and HVAH

The investigator sent an introductory letter and questionnaire booklet to the spouses of patients on the heart transplant waiting list at LUMC and HVAH (see Appendix K). Names and addresses of the spouses at LUMC were obtained from the HT coordinator at LUMC. The names and addresses of the spouses at HVAH were readily available to the investigator because of being employed as the HT coordinator at HVAH. Patients were discussed and listed for transplant at a weekly heart transplant board meeting. The list of potential subjects was updated each week at this meeting and the investigator attended these meetings on a regular basis. The listing date for the patient was readily available on the LUMC/HVAH transplant list distributed weekly at the board meeting.

The introductory letter explained the purpose of the study, what to do with the booklet, that the investigator would contact them in about 1 week to answer any questions, a date by which to return the booklet (2 weeks from the date the booklet was mailed), payment for completion of the booklet, and a brief note of gratitude in advance for their participation. A formal consent form was waived by the IRB at LUMC and HVAH since consent was implied by the subject completing the booklet. A return self-addressed stamped envelope was sent along with the booklet. Completed questionnaires were mailed back to the investigator. Spouses were paid $5 for completion of the booklet; the $5 along with a letter of thanks was mailed to the participant within one month of receiving the booklet.

Booklets were coded with a study number at the top of the cover page. A master list was kept by the investigator with the study number and names of the subjects. If subjects indicated that they did not want to participate in the study when the phone call for questions was made, they were not contacted further. If, however, subjects indicated that they would participate in the study and did not return the booklet within one week of the return date indicated in their letter, another cover letter and booklet were mailed to the subject. If the subject still did not respond, a phone call was made to the subject. If there was still no response, the subject was not contacted further. Subjects were contacted by the investigator to retrieve data on any questions that were not answered.

UAB

The procedure for UAB was similar to the one described above except that a consent form was required by the UAB IRB. The UAB NIH study site coordinator had the names and addresses of the spouses of patients waiting for heart transplant readily available to her. A similar cover letter, a consent form (see Appendix L), and the same booklet were sent to the UAB spouses. The UAB site coordinator called the spouses for questions within 1 week of mailing the booklet to them. The UAB coordinator notified the investigator if anyone refused to participate at that time. The spouse's name, address, phone number, booklet number, the date the booklet was mailed, and the date the patient was listed for transplant were mailed to the investigator when the booklet was sent to the subject.

The booklets were returned to the UAB site in an effort to increase response rate. The UAB site coordinator in turn mailed the booklet to the investigator. The investigator followed up on missing data and nonresponders. The letter of thanks contained both the investigator's signature and the UAB study site coordinator's signature. The thank-you letter and check were mailed to the UAB site coordinator for her signature.

Ethical Considerations

This study had been approved by the Institutional Review Boards at LUMC, HVAH, and UAB (see Appendix M for IRB approval forms). LUMC and HVAH waived a formal informed consent form. A cover letter describing the study was enclosed with the questionnaire booklet. The participant's completion of the booklet implied their consent to participate.

The risks of the study were minimal. No subjects suffered any adverse effects from participating in this study. Study booklets were coded so that the subject's identity was not revealed. A master list of the subject's name, address, phone number, and study number was kept in a locked drawer in the investigator's HVAH office. Study booklets and related materials were kept in a file cabinet in the investigator's HVAH office. All information obtained from this study will remain completely confidential.

CHAPTER IV

RESULTS

Statistics

The following statistics were used to study the quality of life in spouses of patients awaiting heart transplantation: descriptive methods (frequencies, percents, and measures of central tendency), t-tests, analysis of variance, Pearson correlations, and multiple regression. Level of significance was set at 0.05.

Frequencies and percents were used to describe selected demographic variables such as the data collection site, income, patient status, and gender. T-tests were used to examine differences in scores based on dichotomous variables such as gender and working status. Analysis of variance (ANOVA) was used to show differences in the impact of the transplant experience and stressor variables. Pearson correlations were used to show relationships between major study variables and subscale scores.

Multiple regression was used to determine predictors of quality of life in spouses of patients awaiting heart transplantation. Residuals were examined for normality, linearity, and independence of error. Independent variables were examined for multicollinearity via inspection of the correlation matrix, tolerances, and variance inflation factors. Outliers were identified by Mahalanobis' Distance, and their influence was determined by Cook's Distance.

There was very little missing data for this analysis. Subjects were contacted by phone or mail to retrieve missing data points on returned questionnaires. Four subjects with missing data were not contacted because their spouse had died or been taken off the heart transplant (HT) list shortly after the questionnaire was returned. Each of the subjects had less than 0.02% missing data (8 or less unanswered questions for the entire booklet of 6 tools). Subscale means for the individual subject were used for the missing data points. Three subjects indicated on their questionnaire that they did not wish to answer the income question, and so they were not included in any income analysis.

Descriptive Statistics on Major Variables

Quality of Life

Quality of life data were obtained from three sources: (1) an overall quality of life (QOL) rating, (2) a total score from the Ferrans and Powers Quality of Life Index (QLI) which measures life satisfaction as a major dimension of QOL, and (3) a composite score from these two measures. The composite QOL score was computed by converting the QOL rating and the QLI score to z-scores and then adding them together. This was done to obtain a more comprehensive view of quality of life because quality of life is more than just life satisfaction, and there is a limit to the number of dimensions of QOL that can be measured in one study. The QLI incorporates the four major domains of quality of life cited in the literature. Additionally, the overall quality of life rating may encompass factors not included in the QLI or perhaps not measurable item by item.

Most spouses rated their overall quality of life as good. On a scale of 1-10, the mean quality of life rating was 7.18 (SD = 1.95; obtained range = 2-10). Most subjects (50.6%) rated their quality of life as good, 43.5% as fair, and 5.9% as poor.

Proportional scores were used for comparison across subscales because the number of items varied per subscale which would then result in differing potential scores for each subscale, thus making comparability difficult. The total QLI proportional scores (satisfaction weighted by importance) ranged from .43 to .88 ($\overline{X}$ = .72, SD = .10). The range of proportional scores attainable on the overall QLI and subscales is .00-1.00. Thus, a mean proportional score of .72 represents moderately good to good quality of life. Mean proportional subscale scores were also relatively high: socioeconomic = .80 (SD = .14, obtained range = .34-1.00); family .80 (SD = .14, obtained range = .35-1.00); psychological = .74 (SD = .18, obtained range = .09-1.00); and health/functioning = .69 (SD = .15, obtained range =

.34-.97). Thus, subjects rated the quality of their family and socioeconomic lives highest, followed by the psychological and health/functioning aspects of their lives.

Pre-HT spouses were most satisfied with: (1) the relationship with their partner ($\bar{X}$ = 5.56 on a 1-6 scale, SD = 0.84); (2) children ($\bar{X}$ = 5.49, SD = 0.75); (3) friends ($\bar{X}$ = 5.40, SD = 0.77); (4) personal faith in God ($\bar{X}$ = 5.36, SD = 1.10); and (5) neighborhood ($\bar{X}$ = 5.32, SD = 1.05). The five areas subjects were least satisfied with were: (1) amount of stress/worries in life ($\bar{X}$ = 2.94, SD = 1.48); (2) ability to travel on vacations ($\bar{X}$ = 3.61, SD = 1.47); (3) family's health ($\bar{X}$ = 3.87, SD = 1.70); (4) sex life ($\bar{X}$ = 4.08, SD = 1.67); and (5) peace of mind ($\bar{X}$ = 4.11, SD = 1.58).

The five top ranked QLI *importance* items were: (1) family's health ($\bar{X}$ = 5.93 on a 1-6 scale, SD = 0.30); (2) family's happiness ($\bar{X}$ = 5.92, SD = 0.32); (3) children ($\bar{X}$ = 5.89, SD = 0.62); (4) relationship with partner ($\bar{X}$ = 5.87, SD = 0.61); and (5) peace of mind ($\bar{X}$ = 5.80, SD = 0.51). Those items which were *least* important were: (1) not having a job ($\bar{X}$ = 2.94, SD = 2.14, N = 20); (2) ability to travel on vacations ($\bar{X}$ = 4.34, SD = 1.47); (3) amount of stress/worries in life ($\bar{X}$ = 4.56, SD = 1.36); (4) sex life ($\bar{X}$ = 4.80, SD = 1.10); and (5) leisure time activities ($\bar{X}$ = 4.94, SD=0.92). (Of note, only scores of those not working were computed for the item "not having a job.") A complete rank-ordering of the QLI items by means appears in Appendix N.

The correlations between the satisfaction and importance subscales of the QLI were: overall, r = .51, health/functioning, r = .42, socioeconomic, r = .44, psychological/spiritual, r = .55, and family, r = .10. Thus, the satisfaction and importance subscales were lowly to moderately correlated. Thus, those items rated as most satisfied may not always have been rated as most important.

In summary, subjects were most satisfied with their family and faith in God; similarly, family items were also rated as most important. Subjects were least satisfied with the amount of stress or worries in their life and the ability to take vacations; however, these items were also rated as least important. Conversely, subjects were least satisfied with their family's health and rated this item among the most important.

Health and Demographic Variables

The following health and demographic variables were delineated as potential stressors within the Lazarus Stress and Coping Framework outlined for this study: duration of time the patient was on the HT waiting list, the spouse's perception of the patient's health, the subject's health, and the subject's employment status. Patient partners were waiting for a heart an average of 222 days (SD = 283.50; range = 1 day-3.7 years). A median may be more reflective of the average waiting time since the range was so large; the median wait time was 98 days.

Spouse's rating of the patient's health was a mean of 4.39 (SD = 2.45) on a one-item rating scale ranging from 1-10 (1 = worse health). A frequency distribution showed that 41% of the subjects rated their patient partner's health as poor, 46% as fair, and 13% as good. Such scores indicate that most subjects perceived the patient's health to be moderate to poor. The patient's current hospitalization status was used as an objective measure of the patient's health. Twelve patients (14.1%) were in the intensive care unit, one patient (1.2%) was hospitalized on a general floor, and 72 patients (84.7%) were at home at the time the survey was completed.

The subject's mean rating of his/her own health was good, 8.12 (SD = 1.80) on a scale of 1-10. Seventy-seven percent rated their health as good, 20% as fair, and 3% as poor. The number of hours worked outside the home was used to determine the spouse's employment status. The mean number of hours that spouses worked outside the home was 27.59 (SD = 17.96; range = 0-55 hours). The majority of subjects (76%) were employed.

Stress Appraisal

Overall stress rating. An overall level of stress rating was included in this study as an indicator of stress from all sources because one practical tool cannot possibly measure all aspects of stress. On a 1-10 scale, subjects rated their mean overall level of stress while their spouse was waiting for a heart transplant as 7.32 (SD = 2.56; obtained range = 1-10). Thirteen percent rated their overall level of stress as low, 22% as moderate, and 65% as high. This indicates that spouses were under a great deal of stress during this waiting period.

Spouse Transplant Stressor Scale (STSS). The total score for the STSS was computed by recoding the "not applicable" scores to zero and summing the scores. The mean proportional total stressor score was .31 (SD = .16; obtained range = .01-.74). The possible range of proportional scores was .00-1.00. Mean proportional scores for the stressor subscales were: transplant stressors = .39 (SD = .18; obtained range = .02-.78); responsibility stressors = .34 (SD = .28; obtained range = .00-1.00); socioeconomic stressors = .30 (SD = .23; obtained range = .00-.81); and stressors related to self = .29 (SD = .19; obtained range = .00-.94). Thus the transplant stressors were the most stressful, followed by responsibility stressors, socioeconomic stressors and stressors related to self.

A complete rank-ordering of items for the STSS by mean rating appears in Appendix O. The five top ranked stressors were: (1) afraid that the patient spouse might die ($\overline{X}$ = 2.34 on a 0-3 scale, SD = 0.96); (2) not knowing when the transplant will take place ($\overline{X}$ = 2.28, SD = 0.92); (3) not knowing <u>if</u> the transplant will take place ($\overline{X}$ = 2.19, SD = 1.02); (4/5) not knowing if a heart will come along ($\overline{X}$ = 2.02, SD = 0.91), and waiting for the transplant ($\overline{X}$ = 2.02, SD = 0.91). All of the five top ranked items related directly to the transplant experience.

The five factors that were <u>least</u> stressful were: (1) patient's alcohol and/or drug abuse ($\overline{X}$ = 0.07 on a 0-3 scale, SD = 0.34); (2) subject's alcohol and/or drug abuse ($\overline{X}$ = 0.09, SD = 0.39); (3) losing job ($\overline{X}$ = 0.24, SD = 0.68); (4) having to get a job because of spouse's illness ($\overline{X}$ = 0.25, SD = 0.75); and (5) worrying about the effect of surgery on the spouse's physical appearance ($\overline{X}$ = 0.26, SD = 0.58). The first four least stressful items were rated as <u>not applicable</u> stressors by the majority of the subjects, whereas worrying about the effect of transplant on the spouse's physical appearance was rated as <u>not stressful</u> by majority subjects.

<u>Impact of the transplant experience.</u> The last stress appraisal component delineated in the conceptual model was the impact of the transplant experience on the spouse subject. The response format for this one-item question ranged from -5 (very negative impact), to 0 (no impact), to +5 (very positive impact). Approximately one-third (31%) of the subjects reported that the transplant experience had a negative impact on their life, 3% reported no impact, and

66% reported a positive impact. The mean score for this item was 1.56 (SD = 3.34; obtained and possible range = -5 to +5), indicating that most spouses felt that the transplant experience had a slightly positive impact on their life.

Coping

Three measures of coping were used to assess different aspects of the coping process: an overall coping ability rating, the Jalowiec Coping Scale (JCS), and the Family Inventory for Resource Management (FIRM) scale. The overall rating represents the subjects' ability to cope with their spouse being on the HT waiting list. The Jalowiec Coping Scale assesses the extent of use and effectiveness of eight coping styles utilized to manage the stress of waiting for a heart transplant. The FIRM assesses the resources available to a family to manage stress and crisis.

Coping ability. Spouses rated their overall coping ability as 8.15 (SD = 1.74; range = 3-10) on a scale of 1-10. This mean indicates that subjects perceived that they were coping well with their spouse being on the HT waiting list. Indeed, 77.6% reported they were coping well, 18.8% fair, and 3.5% poor.

JCS. The JCS measures the use and effectiveness of eight coping patterns. There are a variety of ways to compute the scores. The adjusted coping effectiveness scores correlated best with the quality of life scores.

Therefore, for this summary section, the adjusted coping effectiveness scores are reported.

The adjusted coping effectiveness scores were computed by dividing the effectiveness scores for the total scale and for each subscale by the total number of coping methods used by the subject for each subscale. The possible range of scores for this method of computation is 0-3. The mean adjusted overall coping effectiveness score for the sample was 1.73 (SD = .45; range = .63-2.70) indicating that the coping strategies used were fairly effective in coping with their spouse waiting for HT. Mean adjusted effectiveness scores for the eight subscales were as follows: supportant, 2.22 (SD = .56; range = .5-3); optimistic, 2.05 (SD = .56; range = .5-3); confrontive, 2.01 (SD = .56; range = .5-3); palliative, 1.82 (SD = .57; range = .5-3); self-reliant, 1.67 (SD = .60; range = .14-3); fatalistic, 1.27 (SD = .77; range = 0-3); evasive, 1.16 (SD = .52; range = .25-3); and emotive, 0.77 (SD = .65; range = 0-2.75). Thus, positive types of coping (supportant, optimistic, confrontive, and self-reliant) were more effective than negative types of coping (fatalistic, evasive, and emotive). (The palliative subscale has both positive and negative coping items.)

The five individual coping methods <u>used most</u> were: (1/2) prayed or put trust in God ($\overline{X}$ = 2.73 on a 0-3 scale, SD = 0.56) and tried to think positively ($\overline{X}$ = 2.73, SD = 0.52); (3) tried to handle things one step at a time

($\bar{X}$ = 2.59, SD = 0.66); (4) thought about the good things in life ($\bar{X}$ = 2.55, SD = 0.68); and (5) tried to keep busy ($\bar{X}$ = 2.49, SD = 0.89). The five coping methods <u>used least</u> were: (1) told yourself that the problem was someone else's fault ($\bar{X}$ = 0.32, SD = 0.76); (2) took a drink to make yourself feel better ($\bar{X}$ = 0.38, SD = 0.74); (3) did something impulsive or risky that the person would not usually do ($\bar{X}$ = 0.39, SD = 0.73); (4) tried to get out of the situation ($\bar{X}$ = 0.45, SD = 0.72); and (5) told yourself you were just having some bad luck ($\bar{X}$ = 0.47, SD = 0.81).

The five <u>most effective</u> coping methods were: (1) prayed or put trust in God ($\bar{X}$ = 2.62 on a 0-3 scale, SD = 0.67); (2) tried to think positively ($\bar{X}$ = 2.46, SD = 0.76); (3) tried to handle things one step at a time ($\bar{X}$ = 2.42, SD = 0.78); (4) thought about the good things in life ($\bar{X}$ = 2.39, SD = 0.87); and (5) tried to keep a sense of humor ($\bar{X}$ = 2.24, SD = 0.85). The five <u>least effective</u> coping methods were: (1) told yourself that the problem was someone else's fault ($\bar{X}$ = 0.08, SD = 0.32); (2) blamed yourself for getting into such a situation ($\bar{X}$ = 0.14, SD = 0.49); (3) ate or smoked more than usual ($\bar{X}$ = 0.21, SD = 0.51); (4) took out tensions on someone else ($\bar{X}$ = 0.25, SD = 0.51); and (5) told yourself you were having some bad luck ($\bar{X}$ = 0.26, SD = 0.64). Thus, the five most used and most effective coping methods were positive coping methods; similarly, the least used and least effective coping strategies were negative coping strategies. JCS items are rank-ordered by mean use and effectiveness in Appendix P.

FIRM. The total score and subscale scores for the FIRM fell within the normative range reported by McCubbin and Comeau (1987) that were obtained from families with sick children (N = 322). The normative data set may or may not be comparable to subjects with spouses awaiting heart transplantation. The mean total FIRM score obtained was 114.61 (SD = 18.54; obtained range = 74-145). The normative range is between 93 and 129. The subscale means were: family strength esteem and communication, 36.81 (SD = 6.73; obtained range = 8-45; normative range = 29-41); family strength mastery and health, 41.59 (SD = 9.28; obtained range = 12-59; normative range = 30-48); extended family social support, 9.73 (SD = 2.34 obtained range = 3-12; normative range = 8-12); and financial well-being, 26.48 (SD = 8.42; obtained range = 8-42; normative range = 19-37). Therefore, the total FIRM score and subscale scores fell within the normative range, meaning that the subjects had adequate family resources available to cope with their spouse waiting for a heart transplant.

The five top-ranked FIRM items by mean were: (1) members of family are known to be good citizens ($\overline{X}$ = 2.80 on a 0-3, SD = 0.51); (2) working members of family are respected by co-workers ($\overline{X}$ = 2.78, SD = 0.62); (3) feel great satisfaction when we can help one another in our family ($\overline{X}$ = 2.65, SD = 0.61); (4/5) it is okay for family members to show positive feelings about each other ($\overline{X}$ = 2.58, SD = 0.75) and members of family respect one another ($\overline{X}$ = 2.58, SD = 0.62).

The five lowest ranked FIRM items by mean were: (1) depend almost entirely on alimony and/or child support ($\overline{X}$ = 0.02, SD = 0.22); (2) depend almost entirely on welfare ($\overline{X}$ = 0.13, SD = 0.53); (3) have written checks knowing there wasn't enough money to cover them ($\overline{X}$ = 0.35, SD = 0.75); (4) our relatives take from us but give little in return ($\overline{X}$ = 0.39, SD = 0.74); and (5) we have more illnesses than others ($\overline{X}$ = 0.41, SD = 0.68). Thus, the majority of subjects had good citizens for family members, respected each other, family members helped each other, and had sufficient financial resources. Most of the lowest ranked items were negative items. Therefore, in terms of resources available for family coping, it is positive that depending on alimony or welfare ranked low. FIRM items are rank-ordered by means in Appendix Q.

Differences Between Means

T-tests were used to examine differences in the stress, coping and QOL variables, based on gender, work status, and objective health status. In addition, ANOVA was used to examine differences in the impact of the transplant experience. Only significant differences are reported.

Gender

Gender differences were found in the following coping methods used: confrontive (female $\overline{X}$ = 19.22, SD = 5.42; male $\overline{X}$ = 13.37, SD = 5.88; t[83] = 2.88, p = .005); optimistic (female $\overline{X}$ = 20.83, SD = 3.96; male $\overline{X}$ = 14.37, SD = 3.50; t[83] = 4.42, p = .000); and palliative (female $\overline{X}$ = 9.81, SD = 2.99; male $\overline{X}$ = 6.00, SD = 2.83; t[83] = 3.44, p = .001). Thus, women used significantly more confrontive, optimistic, and palliative coping strategies than men. Additionally, women rated the coping strategies they used as significantly more effective than men (female $\overline{X}$ = 1.78, SD = .428; male $\overline{X}$ = 1.28, SD = .375; t[83] = 3.15, p = .002). Gender difference results must be interpreted with caution because the number of men in the sample was small (8 men, 77 women).

No significant gender differences were found in the family resources available for managing stress (FIRM), the overall level of stress rating, the stressor scores on the STSS total scale and subscales, life satisfaction (QLI) total scale and subscales, the overall perceived quality of life rating, and the QOL composite score.

Work Status

The sample was divided into workers and non-workers based on the number of hours worked outside the home. Those who worked outside the home were categorized as workers (N = 65); those who worked zero hours outside the home were categorized as non-workers (N = 20). Significant differences were found on the total number of stressors (non-workers $\bar{X}$ = 42.75, SD = 22.69; workers $\bar{X}$ = 60.20, SD = 30.04; t[83] = 2.39, p = .019), and also on three of the stressor subscales: socioeconomic stressors, responsibility stressors, and stressors related to self. Subscale means and significance levels were as follows: socioeconomic stressors (non-workers $\bar{X}$ = 4.10, SD = 4.28; workers $\bar{X}$ = 9.47, SD = 6.15; t[83] = 3.64, p = .000); responsibility stressors (non-workers $\bar{X}$ = 3.50, SD = 3.85; workers $\bar{X}$ = 6.13, SD = 4.59; t[83] = 2.33, p = .022); and stressors related to self (non-workers $\bar{X}$ = 13.65, SD = 10.43; workers $\bar{X}$ = 21.75; SD = 13.26; t[83] = 2.50, p = .014). Thus, those who worked outside the home reported significantly more total stressors, socioeconomic stressors, responsibility stressors, and stressors related to self.

Based on the number of hours worked, no significant differences were found in the quality of life scores, the FIRM scores, the JCS scores, the overall level of stress, the perceived coping ability, or the health rating of the spouse (subject).

Patient's Objective Health Status

Based on the objective health status measure, the patients were divided into the sickest patients (patients in ICU, N = 12) and all others (N = 73). This type of ranking is comparable to the United Network for Organ Sharing (UNOS) priority classification system for patients awaiting heart transplantation. Significant differences were found in socioeconomic stressors (ICU $\bar{X}$ = 12.75, SD = 7.82; others $\bar{X}$ = 7.47, SD = 5.59; t[83] = 2.86, p = .005) and financial resources available for coping (ICU $\bar{X}$ = 21.58, SD = 10.16; others $\bar{X}$ = 27.29, SD = 7.90; t[83] = 2.22, p = .029). Thus, subjects whose spouses were awaiting transplant in the ICU experienced more socioeconomic stressors and had less financial resources available for coping than those whose spouses were not in the ICU.

Impact of the Transplant Experience

Analysis of variance was used to examine differences in scores based on those reporting a positive impact from the transplant experience (65.9%), no impact (3.5%), and a negative impact (30.6%). Significant differences were found between those reporting a positive impact (PI) versus those reporting a negative impact (NI) on the following variables: quality of life composite score (PI $\bar{X}$ = .338, SD = 1.60; NI $\bar{X}$ = -.692, SD = 1.84; F = 3.28, p = .043); total stressor score (PI $\bar{X}$ = 50.16, SD = 28.57; NI $\bar{X}$ = 68.58, SD = 28.10; F = 3.75, p = .028); responsibility stressors (PI $\bar{X}$ = 4.66, SD = 4.40, NI $\bar{X}$ = 7.58, SD = 4.48; F = 4.22, p = .018); and stressors related to self (PI $\bar{X}$ = 16.86, SD = 11.12; NI $\bar{X}$ = 25.77, SD = 14.54; F = 4.70, p = .011). Thus, those who reported that the transplant experience had a positive impact on their life reported significantly higher quality of life, and significantly less total stressors, responsibility stressors, and stressors related to self. No significant differences were found with the group who reported that the transplant experience had no impact on their life. The lack of significance, however, was probably due to the small number of subjects in that group.

Pearson Correlations

Quality of Life Correlations

Correlations between quality of life and study variables were examined. Correlations for the three quality of life scores (QLI total score, QOL rating, QOL composite score) are depicted in Appendix R. For the purpose of this discussion, the quality of life composite score (QOLCS) will be used, because correlations were generally better, and theoretically, it is an additive combination of the previous two scores and thus taps into QOL more comprehensively.

Health and demographic variables. Beginning with the health and demographic stressor portion of the conceptual framework, the spouse's own health was strongly correlated with QOLCS ($r = .476$, $p = .000$). Thus, the better the spouse rated his/her health, the better QOL tended to be. No significant relationships were found between the QOLCS and income, the subject's perception of the spouse's health, the number of days the spouse had been waiting for a heart transplant, or the number of hours the subject worked outside the home.

<u>Stress Appraisal Variables.</u> All of the stress appraisal variables correlated very significantly with quality of life. The QOLCS was negatively associated with the overall stress rating (r = -.460, p = .000) and with the total stressor score (r = -.496, p = .000). QOLCS correlations for the stressor subscales were as follows: (1) stressors related to self (r = -.472, p = .000); (2) transplant stressors (r = -.401, p = .000); responsibility stressors (r = -.389, p = .000); and socioeconomic stressors (r = -.380, p = .000). Thus, as expected, quality of life was adversely affected by increasing levels of overall stress and different types of stressors. In addition, the positive impact of the transplant experience was associated with higher QOLCS (r = .280, p = .009).

<u>Coping Variables.</u> Coping variables were very significantly related to quality of life. Better coping ability correlated with higher QOLCS (r = .524, p = .000). Overall coping effectiveness, as measured by the adjusted JCS score, also correlated positively with the QOLCS (r = .453, p = .000) so that the more effective the coping styles were, the better the QOLCS. Significant QOLCS correlations with the JCS coping <u>effectiveness</u> subscales were as follows: supportant (r = .365, p = .000); confrontive (r = .364, p = .001); optimistic (r = .347, p = .001); self-reliant (r = .343, p = .001); palliative (r = .337, p = .002); and evasive (r = .241, p = .027). Thus, the effectiveness of

six coping styles (supportant, confrontive, optimistic, self-reliant, palliative, and evasive) was related to higher quality of life.

Interestingly, QOLCS showed a significant negative correlation with the _use_ of the following coping styles: (1) emotive (r = -.488, p = .000); (2) evasive (r = -.423, p = .000); (3) fatalistic (r = -.407, p = .000); and (4) palliative (r = -.267, p = .014). Thus, the use of negative coping styles adversely affected QOL. Of note, the _use_ of evasive coping methods was negatively associated with QOL; however, if evasive coping methods were found to be effective, they were positively associated with QOL.

Health-Related Correlations

Number of Days Waiting for a Transplant. The longer the wait for a heart donor, the worse was the impact of the transplant experience on the spouse (r = -.225, p = .039). The following stressor variables were not significantly related to the number of days the patient waited for a HT: overall level of stress rating, total stressor score, or any of the four types of stressors. Thus, contrary to expectations, it does not appear that greater stress increases with a longer waiting time for transplantation.

Subject's Health. All of the QLI subscales correlated significantly with the subject's health, as follows: (1) health and functioning (r = .502, p = .000); (2) psychological/spiritual (r = .425, p = .000); (3)

socioeconomic (r = .260, p = .016); and (4) family (r = .256, p = .018). These results indicate that healthier subjects were more satisfied with these areas of their lives. Contrary to expectations, none of the stress appraisal variables correlated significantly with the subject's health. Thus, the overall level of stress or types of stressors experienced by the subject did not impact on the subject's health.

Perceived Health of the Patient. A significant relationship was found between the perceived health of the patient and the transplant stressor subscale score (r = -.258, p = .017). Thus, the stressors associated with the transplant as experienced by the spouse were significantly related to the perception of the patient's health. No significant relationships were found between the perceived health of the patient and the following variables: overall level of stress, total stressor score, stressors related to self, responsibility stressors, socioeconomic stressors, or the impact of the transplant experience.

Stress Appraisal Correlations

Overall Level of Stress. Subjects with more stress reported poor coping ability (r = -.299, p = .005). The overall level of stress was also negatively and significantly associated with total family resources for coping (r = -.340, p = .001), health and mastery family resources for coping (r = -.413, p = .000), and esteem and communication family resources for coping (r = -.273, p = .011). Thus, higher levels of stress were associated with less family resources available for coping, both overall and specific types.

The overall level of stress also correlated significantly and negatively with many coping variables, as follows: overall coping effectiveness (r = -.353, p = .001) and the <u>effectiveness</u> of six coping styles: (1) self-reliant (r = -.297, p = .006); (2) optimistic (r = -.276, p = .011); (3) palliative (r = -.271, p = .013); (4) supportant (r = -.234, p = .031); (5) fatalistic (r = -.218, p = .050); and (6) confrontive (r = -.217, p = .046). Thus, higher levels of stress were associated with less overall effectiveness of coping strategies and with less effectiveness of self-reliant, optimistic, palliative, supportant, fatalistic, and confrontive coping. A greater overall level of stress was related to the <u>use</u> of more emotive (r = .275, p = .011), palliative (r = .258, p = .017), self-reliant (r = .215, p = .048), and evasive (r = .211, p = .053) coping.

In addition, the overall level of stress correlated significantly with the total stressor score (r = .615, p = .000) and all of the STSS subscales: (1) transplant stressors (r = .640, p = .000); (2) stressors related to self (r = .495, p = .000); (3) responsibility stressors (r = .494, p = .000); and (4) socioeconomic stressors (r = .412, p = .000). Thus, subjects with higher stressor scores from the STSS reported higher overall levels of stress as assessed by the one-item rating.

STSS. The total stressor score correlated significantly and negatively with the following: (1) health and mastery family resources (r = -.679, p = .000); (2) health and functioning satisfaction (r = -.480, p = .000); (3) psychological satisfaction (r = -.451, p = .000); (4) socioeconomic satisfaction (r = -.425, p = .000); (5) total number of family resources for coping (r = -.407, p = .000); (6) family satisfaction (r = -.362, p = .001); (7) impact of the transplant experience (r = -.339, p = .001); (8) overall coping effectiveness (r = -.307, p = .004); and (9) effectiveness of evasive coping (r = -.244, p = .016). Therefore, those with more stressors had less total and health and mastery family resources available, were less satisfied with health/functioning, psychological, socioeconomic, and family areas of life, felt their evasive coping and overall coping were less effective, and reported a more negative impact of the transplant experience.

A higher total stressor scale score correlated significantly with a greater use of the following types of coping strategies: (1) evasive (r = .399, p = .002); (2) fatalistic (r = .367, p = .001); (3) emotive (r = .363, p = .001); (4) palliative (r = .326, p = .002); and (5) self-reliant (r = .212, p = .052).

Table 2 summarizes those variables negatively correlated with the STSS subscales and Table 3 summarizes those variables positively correlated with the STSS subscales. As shown, more transplant stressors were associated with less total family resources available for coping; less health/functioning, psychological, and family satisfaction; lower coping ability; less overall coping effectiveness; and use of more negative coping methods. Subjects who reported more socioeconomic stressors experienced the following: less total family resources available for coping; less socioeconomic, health and functioning, psychological, and family satisfaction; and were more negatively affected by the transplant experience. Those under greater socioeconomic stress used more evasive, emotive, and fatalistic coping methods.

Those with more responsibility stressors were negatively affected by the transplant experience. They also were less satisfied with psychological, health/functioning, socioeconomic, and family areas of their life and used more negative coping methods. Lastly, those with more stressors relating to self experienced the following: had less total family resources; were less satisfied with their health and functioning, psychological, socioeconomic and family situation; used more negative coping methods; and were negatively affected by the transplant experience.

TABLE 2

VARIABLES NEGATIVELY CORRELATED WITH STSS SUBSCALES

Variable	TX	SE	RES	SELF
Total FIRM score	r=-.285 p= .008	r=-.466 p= .000	NS	r=-.362 p= .001
Coping ability	r=-.379 p= .000	NS	NS	NS
Overall coping effectiveness	r=-.279 p= .010	NS	NS	NS
Impact of HT experience	NS	r=-.248 p= .022	r=-.317 p= .003	r=-.403 p= .000
Health/functioning satisfaction	r=-.370 p= .000	r=-.391 p= .000	r=-.308 p= .004	r=-.489 p= .000
Family satisfaction	r=-.349 p= .001	r=-.224 p= .039	r=-.312 p= .004	r=-.312 p= .004
Psychological satisfaction	r=-.318 p= .003	r=-.359 p= .001	r=-.324 p= .003	r=-.475 p= .000
Socioeconomic satisfaction	NS	r=-.478 p= .000	r=-.267 p= .013	r=-.442 p= .000

Note: TX = Transplant stressors
SE = Socioeconomic stressors
RES = Responsibility stressors
SELF = Stressors Related to self

TABLE 3

VARIABLES POSITIVELY CORRELATED WITH STSS SUBSCALES

Variable	TX	SE	RES	SELF
Evasive coping used	r=.257 p=.017	r=.352 p=.001	r=.329 p=.002	r=.419 p=.000
Emotive coping use	r=.296 p=.006	r=.305 p=.005	r=.299 p=.005	r=.333 p=.002
Fatalistic coping use	r=.292 p=.007	r=.292 p=.007	r=.320 p=.003	r=.339 p=.001

Note: TX = Transplant stressors
SE = Socioeconomic stressors
RES = Responsibility stressors
SELF = Stressors related to self

<u>Impact of the Transplant Experience.</u> The impact of the transplant experience correlated significantly and positively with the following: (1) family satisfaction (r = .393, p = .007); (2) health and mastery family resources (r = .390, p = .000); (3) psychological satisfaction (r = .341, p = .001); (4) socioeconomic satisfaction (r = .279, p = .010); (5) health and functioning satisfaction (r = .268, p = .013); (6) effectiveness of self-reliant coping methods (r = .262, p = .015); (7) overall coping effectiveness (r = .260, p = .016); and (8) total family resources available for coping (r = .240, p = .027). Thus, those who were positively affected by the transplant experience: had more total and health/mastery family resources; were more

satisfied with the psychological, health/functioning, family, and socioeconomic aspects of their lives; coped more effectively overall; and used more effective self-reliant coping methods.

The impact of the transplant experience correlated significantly and negatively with the following: (1) use of evasive coping (r = -.312, p = .004), (2) use of fatalistic coping (r = -.246, p = .023), (3) use of emotive coping (r = -.265, p = .014); and (4) number of days the patient waited for a heart (r = -.225, p = .039). Thus, those using more negative coping strategies and waiting longer for a transplant reported a more negative impact from the transplant experience.

Coping Correlations

Perceived Coping Ability. Overall coping ability correlated significantly and positively with the following: (1) esteem and communication family resources (r = .414, p = .000); (2) total family resources available for coping (r = .404, p = .000); (3) effectiveness of optimistic coping (r = .384, p = .000); (4) satisfaction with health and functioning (r = .374, p = .000); (5) overall coping effectiveness (r = .360, p = .001); (6) family satisfaction (r = .346, p = .001); (7) socioeconomic satisfaction (r = .324, p = .002); (8) psychological satisfaction (r = .300, p = .005); (9) effectiveness of self-reliant coping (r = .298, p = .006); (10) effectiveness of confrontive coping (r = .289, p = .007); (11) extended family social support (r = .270, p = .012); (12) financial resources (r = .254, p = .019); (13) effectiveness of supportant coping (r = .223, p = .040); and (14) effectiveness of palliative coping (r = .216, p = .049). Therefore, those spouses who felt they were coping better had more total, esteem/communication, financial, and extended family resources available for coping. In addition, they were more satisfied with their health/ functioning, socioeconomic, family, and psychological situation. Their overall, optimistic, palliative, and self-reliant coping strategies were more effective.

Greater coping ability was significantly related to less use of three negative coping styles: emotive (r = -.557, p = .000), evasive (r = -.342, p = .002), and fatalistic (r = -.337, p = .002).

Coping Strategies (JCS). The overall effectiveness of coping, as measured by the adjusted JCS score, correlated significantly with the total FIRM score and all of the FIRM subscales, as follows: (1) total family resources available for coping (r = .478, p = .000); (2) health and mastery family resources (r = .406, p = .000; (3) esteem and communication family resources (r = .355, p = .001); (4) extended family social support (r = .308, p = .004); and (5) financial well-being (r = .236, p = .030). Thus, those with more effective coping mechanisms had more family resources available for coping of all types. Greater coping effectiveness also correlated significantly with more satisfaction with three areas of life on the QLI: psychological (r = .455, p = .000), socioeconomic (r = .389, p = .000), and health/functioning (r = .385, p = .000).

The use of less desirable coping strategies (evasive, fatalistic, emotive) correlated significantly and negatively with the life satisfaction and family resource variables listed in Table 4. In addition, the use of emotive coping correlated significantly and negatively with financial resources (r = -.228, p = .036). Thus, those who used more negative types of coping (evasive, fatalistic, and emotive) were less satisfied with the health/functioning, family, psychological, and socioeconomic aspects of their lives. In addition, they had less total family resources and specifically less health and mastery family resources available for coping. Lastly, those who used more emotive coping strategies had less financial resources available to them for coping.

Family Resources for Coping. The total score for family resources available for coping from the FIRM correlated significantly with the following: (1) socioeconomic satisfaction (r = .701, p = .000); (2) health and functioning satisfaction (r = .618, p = .000); (3) psychological satisfaction (r = .591, p = .000); and family satisfaction (r = .397, p = .000). Thus, those with greater family resources for coping were more satisfied with all four areas of their lives.

TABLE 4

QLI AND FIRM CORRELATIONS WITH USE OF NEGATIVE COPING

Variable	Evasive	Fatalistic	Emotive
QLI			
Health/functioning satisfaction	r = -.519 p = .000	r = -.443 p = .000	r = -.502 p = .000
Family satisfaction	r = -.397 p = .000	r = -.319 p = .003	r = -.403 p = .000
Psychological satisfaction	r = -.358 p = .001	r = -.392 p = .000	r = -.371 p = .000
Socioeconomic satisfaction	r = -.332 p = .002	r = -.302 p = .005	r = -.400 p = .000
FIRM			
Total family resources for coping	r = -.311 p = .004	r = -.309 p = .004	r = -.426 p = .000
Health/mastery family resources	r = -.499 p = .000	r = -.479 p = .000	r = -.420 p = .000

Multiple Regression

Hierarchical multiple regression was performed using forced entry procedures to determine predictors of the quality of life of the HT spouses during the wait for a heart. The composite quality of life score (QOLCS = QLI score + QOL rating score) was used as the dependent variable. Based on the Lazarus stress and coping model, 72.5% of the variance in spouse QOL was explained by the following eight variables: health of the spouse (subject), objective health status of the patient (ICU vs. not ICU), overall level of stress, total stressor score, impact of the transplant experience rating, overall coping effectiveness, total family resources available for coping, and overall coping ability.

Three variables that were originally in the model (number of days the patient waited for a heart, perceived patient health, and number of hours worked) were deleted because they did not contribute significantly when force entered into the regression equation first. The objective health status of the patient spouse was significant when force entered into the regression equation first. Since the patient's objective health status is also representative of the patient's health, this variable was substituted for the non-significant perceived overall health of the patient rating.

In keeping with the Lazarus Stress and Coping model, the health and demographic variables, or potential stressors, were force entered into the regression equation first. The subject's health and the objective health of the patient accounted for 26.7% unique variance ($F = 14.97$, $p = .000$). The stress appraisal variables were entered next. The overall level of stress, total stressor score from the STSS, and the impact of the transplant rating question accounted for 24% unique variance (F = 12.83, p = .000). Lastly, the coping variables were entered into the equation. The coping ability rating, overall coping effectiveness using the adjusted JCS score, and the total FIRM score accounted for 21.7% unique variance (F = 19.96, p = .000). See Table 5 for the regression summary.

When the standardized beta weights were examined, the variables ranked in importance in the following order: (1) subject's health rating; (2) total FIRM score; (3) coping ability rating; (4) objective health status of the patient; (5) overall level of stress; (6) total stressor scale score; (7) impact of the transplant experience; and (8) overall coping effectiveness.

Testing for Violation of Assumptions

Residuals

The residuals for the above regression equation were analyzed. A Durbin-Watson test for independence of error was 1.50; thus, as desired, errors were not correlated. The normality of the residuals was tested via a histogram of standardized residuals. The distribution represented a normal curve with no outliers beyond three standard deviations from the mean. In the normal probability plot of standardized residuals, points clustered close to the normal probability line, thus supporting normality. A scatterplot of the standardized residuals presented no discernible pattern, and points were scattered equally throughout the plot. Thus, there was no linearity among the residuals, as desired.

TABLE 5

REGRESSION ON THE SPOUSE'S QUALITY OF LIFE (N = 85)

Variable	Unique R^2	Cumulative R^2	Stnd. Beta Weight	F, p
Health	.267	.267	.344	F = 14.97 p = .000
Pt. objective health status			.152	
Overall stress	.240	.507	-.145	F = 12.84 p = .000
Total stressors (STSS)			-.103	
Impact of HT experience			.065	
Total family resources for coping (FIRM)	.217	.725	.337	F = 19.96 p = .000
Coping ability			.278	
Coping effectiveness (JCS)			.040	

Multicollinearity

To assess for multicollinearity, the correlation matrix, tolerances, and variance inflation factors were examined. According to Schroeder (1990), a bivariate correlation ≥ .85, a tolerance ≤ .01, or a variance inflation factor ≥ 10 indicates the presence of multicollinearity among the independent variables in a regression equation. All bivariate correlations fell below the .85 limit; the highest was .61 (see Table 6). The tolerance for all the variables fell well above the .01 limit; tolerances ranged from .516 to .926. Variance inflation factors were well below 10 and ranged from 1.08 to 1.94 (see Table 7). Thus, multicollinearity was not found.

Outliers

Outliers were identified by Mahalanobis' Distance and then examined for their influence on the regression equation by using Cook's Distance. Cook's Distance considers changes in all residuals when an outlier is omitted. Only outliers with a Cook's Distance greater than one influence the regression equation and therefore should be considered for deletion (Stevens, 1986). None of the ten outliers had a Cook's Distance greater than one; thus, no cases were deleted (see Table 8).

Homogeneity of Variance

Homogeneity of variance for the ANOVA equations was demonstrated by non-significant Bartlett-Box F tests (see Table 9). Standardized regression scatterplots for homogeneity of variance showed that the spread of data points was similar along the line for each variable, thus supporting homogeneity of variance.

TABLE 6

CORRELATION MATRIX FOR REGRESSION VARIABLES

	SH	PH	OS	TS	IT	CE	CA	TF
SH	1.000							
PH	-.001	1.000						
OS	-.070	.020	1.000					
TS	-.081	-.190	.615	1.000				
IT	.050	-.040	-.202	-.339	1.000			
CE	.177	-.060	-.353	-.307	.260	1.000		
CA	.063	-.274	-.299	-.274	.175	.360	1.000	
TF	.254	.150	-.340	-.407	.240	.478	.404	1.000

Note. SH = Subject's health
PH = Patient's objective health
OS = Overall stress
TS = Total stressor score
IT = Impact of transplant experience
CE = Overall coping effectiveness
CA = Perceived coping ability
TF = Total FIRM score

TABLE 7

TOLERANCES AND VIFS FOR REGRESSION VARIABLES

Variable	Tolerance	VIF
Subject's health	.926	1.080
Patient's objective health	.894	1.118
Impact of transplant experience	.843	1.186
Perceived coping ability	.769	1.300
Overall coping effectiveness	.681	1.469
Total family resources available for coping	.605	1.651
Overall stress rating	.576	1.736
Total stressor score	.516	1.937

Linearity

Standardized partial regression scatterplots were examined for linearity between QOLCS and all of the independent variables. The strongest linear association was with the total FIRM score and QOLCS. Moderate linear associations existed between QOLCS and the following: subject's health, perceived coping ability, overall level of stress, and the total stressor score. Impact of the transplant experience and the patient's status had weak linear associations. Thus, linearity was supported for all of the variables in the regression equation.

TABLE 8

COOK'S DISTANCE FOR OUTLIERS

Case #	Cook's Distance	Significance
10	.11647	.9992
79	.10097	.9996
85	.09699	.9996
84	.09659	.9996
81	.09121	.9997
55	.09096	.9997
54	.08983	.9997
21	.08715	.9998
36	.07255	.9999
35	.04139	1.0000

TABLE 9

HOMOGENEITY OF VARIANCE FOR ANOVAS

Variable	Bartlett-Box F
QOLCS	F = .778 p = .460
Total stressor score	F = .006 p = .994
Responsibility stressors	F = 1.610 p = .201
Stressors related to self	F = .173 p = .842

Normality Plots

Normal probability plots were examined for each of the major study variables to assess normality. In addition, the Kolmogorov-Smirnov (Lilliefors) statistic for goodness of fit was examined. The level of significance for the Kolmogorov-Smirnov (Lilliefors) test was set at the .01 level. Normality was tested by examination of the detrended plots for the QLI score, the JCS overall coping effectiveness adjusted score, the total FIRM score, the QOLCS score, and the STSS total score. Normality was supported since approximately one-half of the points fell above the zero line and one-half below. Normality was further supported by non-significant Kolmogorov-Smirnov (Lilliefors) tests for all of the above variables.

Skewness and kurtosis were present in some of the data as evidenced by the normality plots and the skewness and the kurtosis statistics. The three quality of life variables were negatively skewed. The QLI score was negatively skewed (skewness = -.6696, SE skew = .2612). A t-distribution was used to determine if the skew was significant at the .01 significance level. Results were as follows (df = 84): t-calculated = -2.53; t-tabled = 2.37. Thus, the distribution was significantly and negatively skewed. This means that more scores fell in the positive end of the scale. However, this makes intuitive sense since the sample was essentially healthy ($\overline{X}$ health rating = 8.12 on a scale of 1-10). Therefore, one would expect higher QOL scores. The amount of kurtosis was not significant.

The overall quality of life rating was negatively skewed as well. The skewness and t-statistics were as follows (df = 84, p = .01): skewness = -.7403, SE skew = .2612, t-calculated = 2.83, t-tabled = 2.37. Thus, quality of life ratings fell in the upper end of the scale. There was no significant kurtosis. The QOLCS was also negatively skewed (skewness = -.7949, SE Skew = .2612). T-distribution results were as follows (df = 84, p = .01): t-calculated = 3.04; t-tabled = 2.37. Thus, the skew was significant at the .01 level. There was no significant kurtosis. These results were expected since the QOLCS is a combination of the QLI and the overall quality of life rating.

The subject's overall health rating and the overall coping ability rating both were significantly and negatively skewed. Skewness and t-values for the subject's health rating were as follows (df = 84, p = .01): skewness = -.1.279, SE skew = .2612, t-calculated = -4.899, t-tabled = 2.37. Skewness and t-values for overall coping ability were as follows (df = 84, p = .01): skewness = -1.319, SE skew = .2012, t-calculated = 5.051, t-tabled = 2.37. This shows that ratings for both variables fell in the high range. No kurtosis was present for the overall health rating variable. Significant positive kurtosis was present for the overall coping ability score. Kurtosis and t-values were as follows (df = 84, p = .01): kurtosis = 1.445, SE kurtosis = .5168, t-calculated = 2.79, t-tabled = 2.37. Such kurtosis indicates that more scores than in a normal distribution fell in the peak of the distribution.

The total stressor score, the JCS overall coping effectiveness score, and the total FIRM score had no significant skewness or kurtosis. Thus, normality was further supported for those variables.

Summary of Findings

The following summarizes the important findings on quality of life in 85 spouses of heart transplant candidates:

1. Over half of the subjects rated their quality of life as good.
2. Subjects were most satisfied with their family and their faith in God and were least satisfied with the amount of stress/worries in their life and their family's health.
3. Higher quality of life correlated significantly with better health of the subject, less stress, a positive impact of HT, better coping ability, more coping effectiveness, greater use of positive coping strategies, and more family resources available for coping.

4. The following variables did not have a significant association with quality of life: the number of days the patient waited for a heart, the subject's perception of his/her spouse's health, and the number of hours worked outside the home.
5. Two-thirds of the subjects rated their overall level of stress as high and subjects rated the HT-related stressors highest and the stressors related to self as the lowest of the four groups of stressors.
6. The top five ranked stressors on the STSS directly related to the transplant experience: afraid spouse might die, not knowing when the HT would take place, not knowing if the HT would take place, not knowing if a heart would come along, and waiting for the transplant.
7. Higher levels of stress were associated with less family resources available for coping and less effective coping strategies.
8. Working subjects experienced significantly more stressors than those not working, specifically as related to socioeconomic, responsibility, and self stressors.
9. None of the stressor or stress appraisal variables were significantly associated with the subject's health.

10. Subjects who reported more stressors experienced the following: less total family resources available for coping; less satisfaction with health/functioning, psychological, socioeconomic, and family aspects of their life; and less effective coping.
11. Approximately one-third of the subjects felt that the transplant experience had a negative impact on their life and two-thirds felt that it had a positive impact.
12. Those who stated that the transplant experience had a positive impact on their life reported less responsibility stressors and self-related stressors, had more family resources available for coping, used more effective coping strategies, and were more satisfied with most areas of their lives. Those reporting a negative impact from the HT experience reported more stressors, and used more negative coping strategies.
13. The longer the patient waited for a heart, the more negative was the impact of the transplant experience on the subject's life.
14. Over three-fourths of the subjects felt that they were coping well with their spouse waiting for a heart transplant. Subjects reporting better coping ability had more family resources available for

coping, found positive coping patterns more effective in dealing with their spouse waiting for a HT than negative coping patterns, and were satisfied with all areas of their lives.

15. The most used and most effective coping methods were prayer, thinking positively, handling things one step at a time, and thinking about the good things in life.
16. Those who used negative coping strategies reported lower QOL, were less satisfied with their lives and had less family resources available for coping.
17. Those with more effective coping strategies had more family resources available for coping and were more satisfied with their lives.
18. Comparing the FIRM scores with normative profiles showed that subjects had adequate family resources available for coping with their spouse waiting for a heart transplant.
19. Those with more family resources available for coping were more satisfied with all areas of their lives.
20. A regression equation using Lazarus' stress and coping model explained 72.5% of the variance in the quality of life of spouses of HT candidates. Eight variables predicted higher QOL in the HT candidate's spouse: better health of the subject,

more family resources for coping, better coping ability, a partner in better health, lower overall level of stress, less stressors, a positive impact of the HT experience, and more effective coping.

CHAPTER V

DISCUSSION

Quality of Life

Quality of Life Rating

Overall, the majority of this sample of 85 spouses of heart transplant candidates (50%) rated their quality of life as good. These results were expected since the sample was not patients with an illness, but spouses of patients. Researchers describe the three major domains of quality of life as physical, psychological, and social (Aaronson, 1991; Ferrans, 1990; Jalowiec, 1990); health is the primary factor associated with the physical domain. In this sample, most subjects rated their overall health as good. Thus, it is not surprising that quality of life was also rated high.

Quality of Life Index

Subjects were most satisfied with their family and their faith in God, and least satisfied with the amount of stress/worries in their life and their family's health. Although the same instrument was not used, these results were similar to those reported by 75 post-HT patients in Lough's study (1985). Patients reported greater church or religious involvement since their transplant. The importance of maintaining a strong faith in God was also found in the qualitative pilot study conducted for this dissertation.

As expected, subjects were least satisfied with their family's health. It makes intuitive sense that spouses would not be satisfied with the health of their family when one family member had end-stage heart failure and was awaiting heart transplantation. It was also expected that spouses would not be satisfied with the amount of stress/worries in their life because of the additional strain associated with having a sick or dying family member.

Other studies using Ferrans' QLI were reviewed in order to compare the results of this sample to others. One study has been published thus far using the QLI to assess quality of life in spouses of ill patients. Artinian and Hayes (1992) used the QLI to study quality of life in spouses of coronary artery bypass graft (CABG) patients one-year after surgery. This heart transplant spouse sample reported better quality of life than the CABG spouse sample ($\overline{X}$ = 21.55 vs. 18.44). All of the subscale scores were better as well. One possible explanation is that the HT spouse sample perceived their health as slightly better ($\overline{X}$ = 8.12 vs. 7.92 on a 1-10 scale) than the CABG spouse sample. Since health is a primary component of quality of life, it can be expected that those with better health will report a higher quality of life.

When results of the QLI were compared to previous patient-focused studies using the instrument, results for this sample were lower. The mean total QLI score for this spouse sample was 21.55 (SD = 3.00). The total QLI scores for a patient sample undergoing rehabilitation after a coronary event was 23.24 (SD = 3.56) (Daumer & Miller, 1992), 22.22 (SD = 4.9) for a 6-54 months post-liver transplant sample (Hicks, Larson, & Ferrans, 1992) and 22.35 (SD = 4.04) for a pre-angioplasty sample (Faris & Stotts, 1990).

It is difficult to ascertain why these differences occurred or if these differences are significant. Neither the rehabilitation or liver transplant samples were studied during the critical period of the illness (coronary event or liver transplant). It could be argued that these samples represent "quasi-healthy" samples, or that they adjusted their point of reference in relation to quality of life and therefore were more satisfied with a lower QOL. Although there is no definitive research to support that age and gender influence QOL, it is important to note that there were substantial age and gender differences in the patient and spouse samples. The cardiac rehabilitation sample was predominantly male with a mean age of 58 years; the liver transplant group was almost equally divided by gender with a mean age of 44. The spouse sample was predominantly female with a mean age of 54 years. Only future research involving women and men and a variety of age groups will determine if actual differences exist in the perception of QOL based on age and gender. Therefore, these results are interesting but no substantive conclusions can be drawn.

Quality of Life Composite Score

The subject's health significantly correlated with the QOL composite score (QLI + QOL rating score). This finding is well supported in the literature. In general, physical well-being/health is a primary component of QOL and in most clinical trials is the only aspect of QOL studied. One would expect, therefore, that health would correlate significantly and strongly with QOL. Artinian and Hayes (1992) also found that health correlated significantly and positively with quality of life in spouses of CABG patients.

Significant negative relationships were found with QOLCS and the overall stress rating and the spouse stressor scale scores. The more stress the subject was under, the worse they perceived their QOL. Voepel-Lewis, Starr, Ketefian, and White (1990) reported similar findings when studying family members of kidney transplant patients; and similarly Sexton and Munro (1985) found that more subjective stress in spouses of COPD patients correlated significantly with lower life satisfaction.

The total score for the STSS as well as all of its subscales correlated significantly and negatively with QOLCS. Interestingly, although subjects rated the transplant items as more stressful, it was the stressors related to the self subscale that correlated the highest with poor QOLCS. Thus, it was the lack of time and support available for the spouse that were more strongly related to poorer QOL.

Perceived coping ability, overall coping effectiveness, and family resources available for coping had strong positive relationships with QOLCS. The strong relationship between various forms of coping and QOL is supported in the literature (Voepel-Lewis et al., 1990; White, Ketefian, Starr, & Voepel-Lewis, 1990; White, Richter, & Fry, 1992). Voepel-Lewis et al. studied QOL in 50 family members of renal transplant patients using the family version of the Kidney Transplant Questionnaire. The total coping score was the most important predictor of QOL for family members before and after renal transplant. Using the Ketefian and Starr Kidney Transplant Questionnaire, White, et al. (1990) found that the total number of coping strategies used was a significant predictor of QOL in 55 renal transplant patients. Lastly, White et al. (1992) studied adaptation to illness, using the Psychosocial Adaptation to Illness scale (PAIS), in 158 diabetic women. Although the PAIS is not a direct measure of QOL, it has been used as a measure of QOL before and is therefore included in this discussion. White, et al. (1992) used the Lazarus and Folkman Ways of Coping Questionnaire and found that the use of palliative coping was a significant predictor of less successful adaptation, and the use of problem-focused coping did not influence psychosocial adaptation.

The use of negative coping methods (emotive, evasive, fatalistic) correlated significantly and negatively with QOLCS. Interestingly, the _effectiveness_ of an evasive coping style correlated _positively_ with QOLCS; however, the _use_ of an evasive coping style correlated _negatively_ with QOLCS. So, if the subject found that getting away from the problem or avoiding the problem was an effective method of coping, QOL increased. However, if the individual found that to the avoid the problem was ineffective, QOL decreased. From clinical experience and information obtained from the pilot study, many spouses stated that the only way they could "maintain their sanity" was to work full- or part-time and get away from their patient spouse and the transplant for awhile. For some, this evasive method of coping was successful. Another woman, however, felt that she could never escape the transplant even at work. She felt "saddled to her desk" in case the phone would ring and a heart would become available for her husband. Another woman joined a cardiac rehabilitation program to get some time for herself and get away from the constant transplant focus in her home; unfortunately for her, the following week her husband obtained permission from his cardiologist to join her in cardiac rehabilitation! So some spouses try many evasive coping strategies to escape the transplant experience for awhile but are unsuccessful; whereas others manage to escape for awhile and find it very helpful.

The FIRM was used to assess family resources for coping. The FIRM total score and subscales correlated significantly and positively with QOLCS. There is no research directly using the FIRM as an indicator of QOL. It has been used to assess family function (Leavitt, 1990) and marital function (Gilliss, 1984). If one examines the subscales on the FIRM, however, they contain essential elements of quality of life. Esteem and communication assesses psychological family resources available to families. Health and mastery family resources assess the health and physical well-being of one's family. Financial well-being and extended family social support also represent domains of QOL. Therefore, higher scores on the FIRM should correlate with higher QOLCS scores.

Interestingly, the number of days the patient had been waiting for a heart did not correlate significantly with QOLCS, as was expected. Perhaps adjustment and adaptation took place over time so the waiting time did not directly influence the spouse's QOL. In addition, those patients who wait longer for transplantation generally wait at home and are not as sick as those who wait in the ICUs for shorter lengths of time; therefore, the impact of the wait on the spouse's QOL may not have been as great as originally thought.

Surprisingly, the overall rating of the patient's health also did not influence QOLCS. It was postulated that the sicker the patient was, the more negative would be the impact on the spouse's QOL. Artinian and Hayes (1992) found a significant, positive relationship between the perception of the patient's health post-coronary bypass and the subject spouse's QOL. However, no significant relationship was found in the current study. Lack of significance may have been due to the majority of patients being outpatients in the HT study and therefore, the severity of their illness did not affect the spouse's life at the time of this survey. In addition, subjects may have adapted to the chronicity of their spouse's (the patient's) illness, and thus it did not affect their current perception of their own quality of life.

Health Variables

Patient's Health

Subjects rated their spouse's health as moderately bad ($\overline{X}$ = 4.39 on a scale of 1-10, 1 = worse health). A frequency distribution showed that 41% of the subjects rated their spouse's health as poor, 46% as fair, and 13% as good. These result were better than expected. Since patients listed for transplantation have end-stage congestive heart failure and poor exercise tolerance, it was expected that more scores would cluster in the poor range. The higher scores may be a result of the spouses being used to seeing their partners sick for so long. Also, the majority of patients (N = 72, 84.7%) were waiting for their heart at home when the survey was completed. Of note, spouses' rating of their husbands' health one year after coronary bypass surgery was, as expected, substantially higher at 7.14 on a 1-10 scale (Artinian & Hayes, 1992). So, although the HT scores were higher than expected, they were still much lower than a CABG sample who had already had their surgery and were well on their way to recovery.

Stress Appraisal Variables

Overall Stress Rating

As expected, the majority of the sample (65%) rated their overall level of stress as high. High levels of stress in family members of ill patients are well supported in the literature (Artinian, 1991; Bohachick & Anton, 1990; Gilliss, 1984; Mayou et al., 1978a; Sexton & Munro, 1985; Stern & Pascale, 1979). Artinian found that spouses of patients undergoing CABG surgery had moderate amounts of psychological stress at the time of the surgery and lesser amounts of stress 6 weeks after the surgery (measured by Lefebvre and Sadford's Strain Questionnaire). Bohachick and Anton found that spouses of severe cardiomyopathy patients reported higher levels of stress, as measured by the PAIS psychological distress subscale, than their patient partners

(N = 90 couples). Cardiomyopathy spouses also reported experiencing "quite a bit" to "extreme" worry (82%), anxiety (61%), and depression (39%). Gilliss found that spouses reported significantly higher levels of stress than their patient partners. Mayou et al. reported that 38% of their sample (82 wives of MI patients) were moderately to severely distressed. Crying and disturbances of sleep and appetite were the commonest symptoms. Sexton and Munro reported that wives of COPD patients reported significantly higher stress scores, as measured by Chapman's Subjective Stress Scale, than wives of patients without a chronic illness. Stern and Pascale found that 26% of their sample (52 spouses of MI patients) were anxious or depressed at the time of their initial interview. Wives reported symptoms related to stress such as headaches, dizziness, shortness of breath, and chest pain.

In the current study, the overall level of stress was negatively correlated with many of the coping variables. Those reporting higher levels of stress reported less overall coping effectiveness, poor coping ability, and fewer family resources available for coping. Intuitively and theoretically, this makes logical sense. Since coping assists one in managing his/her stress, poorer coping (effectiveness, ability, and resources) would be associated with higher levels of stress.

Those reporting higher levels of stress also reported less effectiveness of six coping styles: self-reliant, optimistic, palliative, supportant, fatalistic, and confrontive. Less effective self-reliant coping, or having to handle problems by yourself in a time of family crisis, would logically seem to increase one's overall level of stress. Many spouses take on additional responsibilities when their patient partner gets sick and may feel overwhelmed so no matter how hard they try, they cannot do everything on their own. In regard to the effectiveness of optimistic coping, intuitively it would make sense that if one cannot maintain a positive outlook, or finds this ineffective in coping, one's stress would be worse.

Less effective palliative coping, or doing things to make oneself feel better, would also contribute to higher stress. If spouses were unable to control their stress by doing things to make themselves feel better, their overall level of stress would naturally be higher. Likewise, if the support systems that one usually used (supportant coping) were not effective or not available, the overall level of stress would increase. Less effective fatalistic coping, or an overall pessimism, was not effective and would seem to naturally increase the overall stress. Lastly, less effective confrontive coping also was associated with increased levels of stress. Confrontive coping is facing up to the problem and using constructive problem-solving skills. Porter et al. (1994) found that the use of confrontive coping was associated with increased stress in 39 HT candidates. If these methods of coping were not effective in dealing with the stress of a spouse awaiting heart transplantation, then the overall level of stress would be increased.

In support of the above results, Neundorfer (1991) measured stress and coping in 60 caregivers of persons with dementia using the Ways of Coping Checklist by Lazarus and Folkman. They found that caregiver stress was significantly and positively related to the use of escape-avoidance, confrontive, accepting responsibility and seeking social support coping. The highest correlations were found with escape-avoidance (r = .40) and seeking social support (r = .38). These results differ slightly from the current study in that Lazarus' Ways of Coping Checklist measures only the use of various coping strategies, whereas the JCS used for this study also assesses the effectiveness of coping strategies. Van Uitert, Eberly, and Engdahl (1989) found that the use of avoidance coping strategies was a significant predictor of less psychosocial adjustment in wives of stroke patients. Nyamathi, Jacoby, Constancia, and Ruvevich (1992) used the Spouse Coping Instrument with 100 spouses of critically ill patients and found that emotion-focused coping was significantly and positively related to emotional distress. Redeker (1992) studied uncertainty and coping in 129 post-CABG patients and found that as uncertainty increased (measured by the Mishel Uncertainty in Illness Scale), so did the use of avoidance and wishful-thinking coping strategies (Ways of Coping Checklist). This seems to suggest that escapist forms of coping may be preferred in uncertain situations. Sutton and Murphy (1989) found that greater use of affective coping was significantly correlated with a higher stressor score in 40 renal transplant patients.

STSS

Subjects rated the transplant stressors on the STSS as the most stressful. Indeed, the top five most stressful items were directly related to the transplant waiting experience. The most stressful item was fear that the spouse might die before a new heart became available. Similarly, Buse and Pieper (1990) reported that the fear of loss of the spouse was most stressful for spouses pre-transplant. In addition, Bedsworth and Molen (1982) found that the greatest threat identified by 20 spouses of recent MI patients was the fear of loss of their mate.

From clinical experience, spouses and patients frequently state that not knowing when or if the transplant will occur is the worse part of the pre-transplant process. Spouses and patients find that the uncertainty and lack of predictability of if or when the transplant will occur leaves them feeling that they have no control over the situation. Such lack of control can lead to increasing levels of stress in many spouses.

Significant differences were found in the stressor scores between those who worked outside the home and those who did not work outside the home. Those who worked outside the home had a significantly higher total stressor score, socioeconomic stressor score, responsibility stressor score, and stressors related to self score. Interestingly, there was no significant difference between the groups in the transplant stressor score. Therefore, workers and non-workers were equally stressed by the transplant experience. Those who worked outside the home tended to be younger and under more socioeconomic strain. This makes intuitive sense in that younger subjects would have more dependent children, and would probably still have mortgage payments. Older subjects may be more financially settled than younger subjects.

Responsibility stressors and stressors relating to self were also significantly higher in the group who worked outside the home. Those working outside the home would probably find added responsibilities for an ill spouse more stressful since they have less time to handle the responsibilities. For example, taking an ill spouse to the clinic may provide a needed break for a subject who does not work outside the home; whereas a working subject may be under a great deal of stress trying to get the time off of work to accomplish the same end. Lastly, those working would have less time for themselves and thus would report more stressors relating to them personally.

The total stressor score on the STSS was significantly and negatively associated with the family resources available for coping, life satisfaction (health and functioning, psychological, socioeconomic, and family domains), and less effective overall coping. Theoretically, these findings are supported. Lazarus and Folkman (1984) define coping as "efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Those with less resources available to cope and with less effective coping would be expected to have higher stressor scores. Those with more stressors would also be expected to be less satisfied with their lives.

Those reporting high stressor scores also used significantly more evasive, fatalistic, emotive, and self-reliant coping strategies. Again, those using negative coping styles had higher stressor scores because negative/less desirable coping does not work well to reduce stress. Christman et al. (1988) reported that greater use of emotive coping strategies correlated significantly with more emotional distress in myocardial infarction patients. Porter et al. (1994) found that the use of evasive coping in HT candidates was significantly associated with increased stress. The use of evasive coping strategies, in this spouse sample, was *positively* associated with the stressor score, and the *effectiveness* of evasive coping was negatively associated with the stressor scores. So, the simple use of evasive coping strategies was associated with higher stressor scores. If however, the evasive coping strategies were effective in coping, then the stressor scores were lower.

Lastly, those with higher stressor scores reported a more negative impact of the transplant experience. Intuitively, this would make sense since those who experience the transplant process as very stressful would perceive it to be more negative. In addition, the transplant experience may add more stressors onto a perhaps already stressful situation. Also, responsibility stressors and stressors related to self impact directly on the subject. Taking on additional responsibility and having less time for self are tangible occurrences that make the experience more difficult for the subject. Conversely, those who would perceive the experience as less stressful would feel that it had a more positive impact on their lives.

Impact of the Transplant Experience

Approximately one-third of the sample reported that the transplant experience had a negative impact on their lives. The remaining two-thirds reported that the transplant experience had a positive impact on their lives, and only 3% reported that the experience had no impact. Families respond to crisis in different ways. Some may respond positively because: (1) some families may grow closer as a result of crisis; and (2) there may be more support given to the spouse by family and friends once the patient is listed for transplantation. Others may feel a more negative impact because: (1) the spouse may be forced to shoulder more family responsibilities; (2) the spouse may need to return to work; (3) this crisis may lead to increasing levels of stress in the family; and (4) the spouse may take on the burden of family problems alone for fear of upsetting the patient.

Next, those who reported the transplant experience had a positive impact on their life reported significantly lower total stressors, responsibility stressors, and stressors related to self than those who reported a negative impact. Sexton and Munro (1985) found that COPD spouses were negatively influenced by role fatigue (taking on extra responsibilities such as caretaker, decision-maker, and errand doer) in relation to life satisfaction. Woods, Haberman, and Packard (1993) studied the family impact of chronic illness in 125 women. They found that women who experienced the most disease-related demands reported poorer family adaptation. Similarly, HT spouses who experience more disease-related demands may perceive a more negative impact from the HT experience. Nolan et al. (1992) also found that as the HT experience became more negative, stress increased.

Those who perceived the transplant experience had a positive impact on their lives were: (1) those who had more family resources available for coping; (2) those who were more satisfied with their lives overall; and (3) those who used more effective coping strategies. These would be factors that could help the spouse to see the HT in a more positive light. It makes conceptual sense that those who have more resources available for coping, use effective coping strategies and are more satisfied with their lives would report a positive impact from the transplant experience.

Spouses of patients who were waiting longer for a heart were more negatively influenced by the transplant experience. They also had a more negative coping style, used more emotive coping, and had more effective evasive coping strategies. From clinical experience, the prolonged period of waiting for a heart is draining on patients and families. Patients and families begin to lose hope of ever getting a heart and become angry (emotive coping). The lack of control over the passive waiting for a heart is not conducive to more action-oriented coping; therefore the development of effective evasive coping strategies would seem appropriate for psychological survival of the prolonged process.

Surprisingly, none of the stress variables were significantly related to the waiting time for transplantation. One would expect that stress would increase with the length of the wait for transplant. Perhaps adaptation and acceptance of the waiting process and the effectiveness of evasive coping strategies limited the stressfulness experienced by the subjects. This finding was supported, however, in a study of 39 HT candidates (Porter et al., 1994); no relationship was found with the overall level of stress and the time the patient was waiting for a heart.

Coping Variables

Three aspects of coping were assessed: coping ability, coping strategies used and their effectiveness, and family resources available for coping.

Perceived Coping Ability

Over three-fourths of the sample felt that they were coping well with their spouse being listed for heart transplantation. Better coping ability was related to more family resources available for coping, greater overall coping effectiveness, and higher life satisfaction. Specifically, overall coping ability was significantly related to the total family resources available for coping, esteem and communication family resources, and extended family social support for coping. Theoretically, these findings support the premise that the more family resources that one has for coping, the better they will cope.

Similarly, those who found optimistic, self-reliant, confrontive, and supportant coping strategies effective in dealing with their spouse waiting for transplant, were better able to cope that those who did not find them effective. Thus, those who found positive coping strategies effective for managing the stress of their spouse awaiting transplantation were better able to cope with the situation. These findings are theoretically sound in that effective, positive coping strategies correlated significantly with a better overall coping ability.

Greater use of negative coping strategies correlated significantly with poorer coping ability because negative coping strategies are not as effective in managing stress.

JCS

As evidenced by the JCS, the coping strategies the subjects used were largely effective in handling the stress of the transplant wait. Positive coping patterns (supportant, optimistic, confrontive, and self-reliant) were more effective than negative coping patterns (fatalistic, evasive, and emotive). This data supports the better coping ability of 78% of the sample. The top coping strategies used were the supportant strategy of prayer and the optimistic strategy of trying to think positively. The use of prayer was also the top coping strategy used by spouses of CABG patients (Penckofer, Jalowiec, Fink, & Hutson-Denekas, 1992).

The most effective coping strategies used by these HT spouses were praying, thinking positively, handling things one step at a time, thinking about the good things in life, and trying to keep a sense of humor. Similarly, Porter et al. (1994) reported that the most effective coping strategies used by <u>patients</u> awaiting HT were humor and thinking positively.

A study that used the 1987 JCS assessed coping styles, hope, and grief resolution in 75 elderly widow(er)s (Herth, 1990). Herth computed the use x effectiveness scores for each subscale for those whose spouse died in a hospital setting, a hospice setting, or a nursing home setting. The range of scores for the three settings will be used for this discussion. The spouses of the HT candidates had lower scores than the widow(er)s on the evasive, fatalistic, and emotive coping patterns. Spouses of HT candidates had higher optimistic, palliative, and supportant coping scores. Similar ranges were found for confrontive and self-reliant coping.

It would be expected that recent widow(er)s would use more negative coping strategies than those who still had hope for the recovery of their spouse. This is also reflected in the use of more optimistic coping strategies by the HT sample. It would also be expected that HT spouses would use more supportant coping behaviors such as depending on others or talking the problem over with family or friends. Many widow(er)s complain about the profound loneliness that confronts them after the death of a spouse. The use of self-reliant and confrontive coping patterns by both groups reflects that they were both confronting the problem and relying on themselves to deal with the death of their spouse or their spouse waiting for a heart transplant about the same.

Kuiper and Nyamathi (1991) used the JCS to assess stressors and coping strategies in patients with automatic implantable cardioverter defibrillators (AICDs). Kuiper and Nyamathi used the adjusted use and adjusted effectiveness scores for the eight JCS subscales, so scores were compared for the AICD patient sample and the HT spouse sample. The spouse sample found all of the coping strategies more effective than the AICD sample. Perhaps these differences occurred because of the type of stressor each sample was coping with. Both groups found positive coping strategies more effective than negative coping strategies.

The overall effectiveness of coping, as measured by the JCS adjusted score, correlated with the FIRM total score and all of the FIRM subscales. Theoretically, this finding is supported in that the more family resources one has available to cope, the more effectively one would cope with family illness. Similarly, those who utilized more effective coping strategies were more satisfied with their psychological, health/functioning, and socioeconomic aspects of their lives.

FIRM

Subjects reported adequate resources for coping as evidenced by the FIRM. All scores obtained on the FIRM were within the normative range reported by its authors; therefore spouses of HT candidates had an average amount of family resources to cope with the stress of waiting for HT. The FIRM was normed on 322 families of children with myelomeningocele or cerebral palsy (McCubbin & Comeau, 1987) but the authors do not delineate the method they used to derive the normed scores. There may be inherent differences in results based on whether the ill member was a child or an adult.

The FIRM has been used in adult populations to study family function after CABG surgery (Gilliss et al., 1990) and family recovery after vascular surgery (Leavitt, 1990). Both authors, however, used adapted versions of the FIRM so specific comparison of mean scores was impossible. Gilliss et al., however, reported that family resources available for coping increased over time for CABG patients (3 and 6 months post-CABG) but decreased for their significant others. Leavitt (1990) reported that family members were reluctant to ask for help after their patient spouse underwent vascular surgery (of note, no other information on the FIRM was reported).

Lastly, those who had more family resources available for coping, reported higher socioeconomic, health/ functioning, psychological, and family satisfaction. These results may have occurred for two reasons. First, it makes logical sense that those with better family resources would be more satisfied with their life. Second, as noted previously, the FIRM uses a similar framework to examine family resources for coping as the QLI uses to examine life satisfaction.

Predictors of Quality of Life

Using the Lazarus stress and coping model, eight variables were entered into a multiple regression equation to explain the spouse's quality of life while awaiting heart transplantation. The eight variables entered into the equation were: the better health of the subject, more family resources for coping, better coping ability, a partner in better health, lower overall level of stress, less stressors, a positive impact of the HT experience, and more effective coping. The eight variables accounted for 72.5% of the variance in explaining the quality of life of HT spouses. Each component of the model explained about the same amount of variance: potential stressors, 27%; stress appraisal variables, 24%, and coping variables, 22%.

These findings are similar to those reported in the literature although no other studies explain as much variance. Only studies assessing the quality of life in spouses of the ill are discussed here. Artinian and Hayes (1992) accounted for 61% of the variance in 39 spouses' quality of life one year after the partner's coronary artery bypass surgery by the following variables: spouse's physical health, the spouse's perception of her own health, and affirmation support. Since stepwise regression was used, the other major study variables (social support, income, and the perception of the partner's health) were statistically forced out of the equation. The correlation between the spouse's (subject's) physical health and their perception of their (subject's) health was .77, so there may have been some multicollinearity in the data. Nevertheless, as with this study, the spouse subject's own health accounted for a substantial amount of the variance in determining quality of life.

Mathieson et al. (1991) assessed quality of life in 30 spouses of laryngectomy patients. Using hierarchical regression, they explained 68% of the variance in the spouse's quality of life by age, sex, medically related needs, and lifestyle variables such as changes in friendships, socializing, and sexual relationships. The variables used by these authors were substantially different than those used in this study; therefore, meaningful comparisons across studies would be difficult.

Sexton and Munro (1985) studied life satisfaction in 76 married women, 46 of whom had husbands with COPD. Using stepwise regression, they found that subjective stress accounted for 28% of the variance, satisfaction with money available 10%, the diagnosis of COPD 7%, and the work status of the wife 4%. Health, quality of sleep, and the frequency of marital relationships did not enter significantly into the regression equation explaining life satisfaction. Stress appraisal variables for this study accounted for 24% of the variance, although if the stress appraisal variables were entered first into the regression equation, they probably would have accounted for more variance. Additionally, it is interesting that the work status of the wife entered the equation significantly. The number of hours worked by this HT sample did not explain a significant amount of QOL variance, even when force entered into the regression equation first. Health did not enter their regression equation as a significant variable; this was surprising since health is a primary component of QOL.

Study Limitations

This study was cross-sectional and queried spouses only once. Therefore it did not address changes over time in the spouse's perception of quality of life and the factors that impacted on QOL. Second, due to sample size concerns and the practical constraints of data collection time, the length of time that the spouse had been adapting to the wait for transplant was not homogeneous. All spouses, regardless of how long they had been waiting for a heart, were queried. Thus, any changes in coping, stress, impact of the HT experience or quality of life that may have occurred during the ongoing process of waiting for a HT were not accounted for.

Future Research

Future research in this area needs to be directed toward studying the spouses over time to determine if their quality of life changes during the longer wait for transplantation as well as post-transplantation. Data from HT spouses needs to be compared and contrasted to HT patients to develop a more comprehensive picture of how HT impacts the family, and in addition, to understand how stress and coping patterns of patients and their spouses affect each other. Perhaps high levels of stress in the spouse adversely affect the patient and vice versa. This information would be beneficial to health care providers as well as to the patient and spouse in order to gain a better understanding of the impact of the HT process on each partner. In addition, other family members, particularly children, need to be studied to ascertain how the HT process affects them. Patients and spouses often express concern about how their children are being affected by their parent waiting for a HT; however, children are often too young to have ready access to hospital support systems and are often cared for by extended family during some or all of the wait for HT. Lastly, using the results from the above research, intervention studies could be designed to help reduce stress and improve the quality of life of spouses during the wait for HT and after.

Implications for Nursing Practice

The data from this study suggest several areas in which nurses can provide assistance to spouses of HT patients. First, the majority of spouses rated their overall level of stress as high; therefore spouses may be more vulnerable to stress-related diseases/disorders. Nurses can encourage spouses to take care of themselves as well as suggest some stress-reducing activities. Spouses rated factors related to the transplant experience as being the most stressful for them. Perhaps being open to talking about such fears with spouses would assist them with coping better.

Spouses who waited longer for a heart transplant reported a more negative impact from the experience. This is an important finding for nurses to recognize. As health care professionals see patients and their families month after month, they may forget the impact of the waiting process on their lives. Patients and spouses are always on call for something that they are not certain will ever happen. It is important to recognize this, ask spouses how they are doing (perhaps away from their patient partner since many of them try to protect their patient partner from stress and worries) and not to forget spouses as they try to cope with the HT experience.

Working spouses reported more responsibility and self-related stressors. In a survival guide for cardiac spouses, Levin (1987) discusses the "right responsibility" for cardiac spouses. Levin states that right responsibility is basing action on an accurate perception of reality and involves encouraging independence. Conversely, overly responsible spouses assume too much responsibility for their patient partner's care. Discussing these issues with spouses of HT patients at the time of the HT evaluation may lessen the spouses' concerns relating to what their patient partner is capable of doing.

Nurses can encourage the use of positive coping styles and discourage the use of negative coping styles. It is important to recognize, however, that if evasive coping was effective in managing the stress of waiting for HT, it positively influenced QOL; therefore effective evasive coping should not be discouraged. However, if nurses see that negative coping strategies are consistently used by spouses and are ineffective in handling stress, referrals for counseling can be made.

The most important information to be obtained from this study by nurses is the recognition that many spouses of HT patients are profoundly affected by the HT process. Nurses must include spouses in their nursing interventions and pay attention to their needs throughout the HT process.

APPENDIX A

TABLE 10

DOMAINS OF QUALITY OF LIFE

Physical	Psychological	Social
Physical function	Level of stress	Ability to communicate
Ambulation & mobility	Coping ability	Role function
Self-care ability	Life satisfaction	Social support
Exercise tolerance	Control over life	Usefulness to others
Ability to work	Meaning of life	Extent of recreational participation
Energy/stamina	Healthy body image	Social interaction
Adequate sleep/rest	Self-acceptance	Satisfaction with sexual life
Nutritional balance	Self-esteem/worth	Marital/family relationships
Absence of pain	No negative mood	Family health/ happiness
Control of symptoms	Psychological well-being	Financial independence
Somatic comfort	Achievement of life goals	Socioeconomic status
Physical independence	Intellectual functioning	Standard of living
Required lifestyle change	Perceived health	Neighborhood
Sexual activity	Seriousness of illness	Employment
Toxicity of treatment	Illness worries	Education
Ability to take care of responsibilities	Illness prognosis	Friendships and social life
Ability to participate in recreational activities	Confidence in treatment	Satisfaction with city and nation
	Acceptability of treatment	
	Satisfaction with treatment	
	Satisfaction with healthcare	
	Adjustment to illness	
	Affect	
	Spiritual aspects	
	Depression	
	Hope	
	Enthusiasm for life/fortitude	

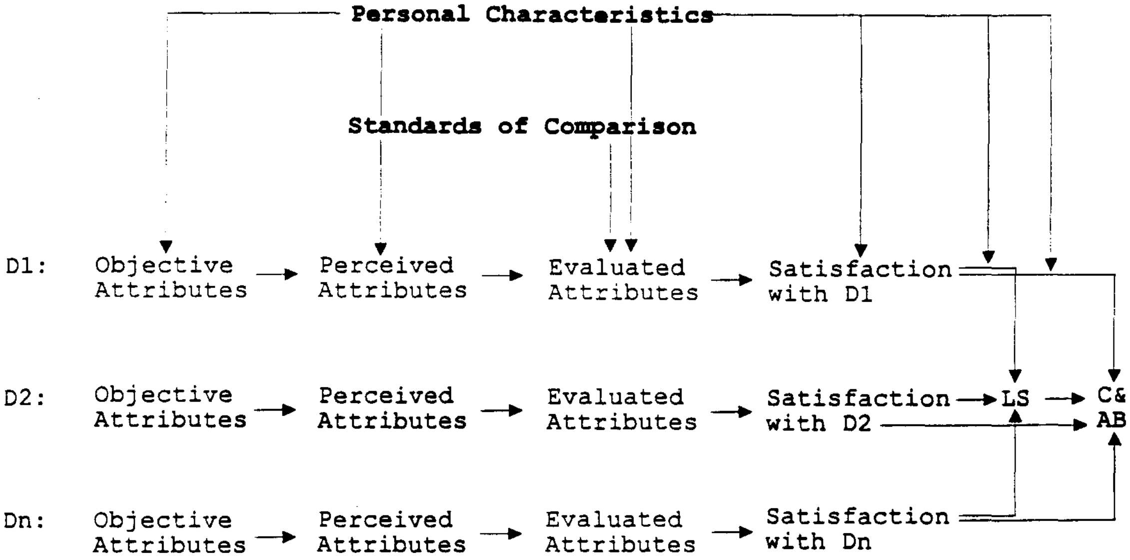
<u>Note.</u> (Ferrans, 1990; Jalowiec, 1990)

APPENDIX B

FIGURE 1

CAMPBELL AND CONVERSE QUALITY OF LIFE MODEL

Model of the Relationship between
Objective Environmental Characteristics
and the
Experienced Level of Satisfaction with Domain



<u>Note.</u>

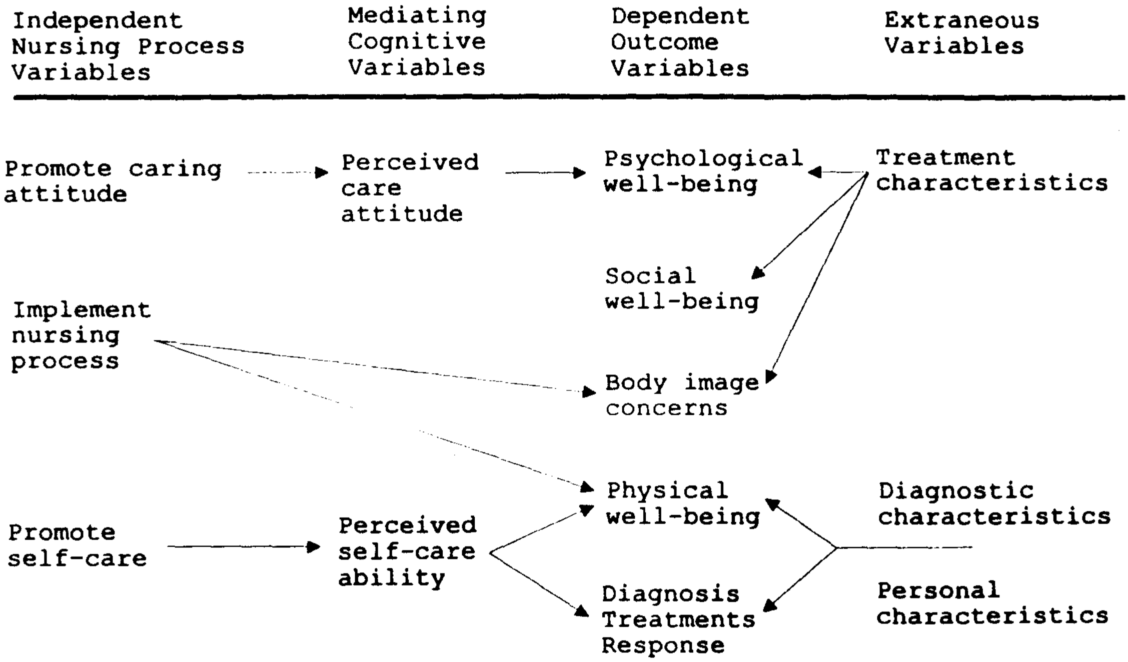
LS=Life Satisfaction
C&AB=Coping and Adaptive Behavior

Campbell, Converse & Rodgers, 1976

APPENDIX C

FIGURE 2

PADILLA & GRANT QOL MODEL

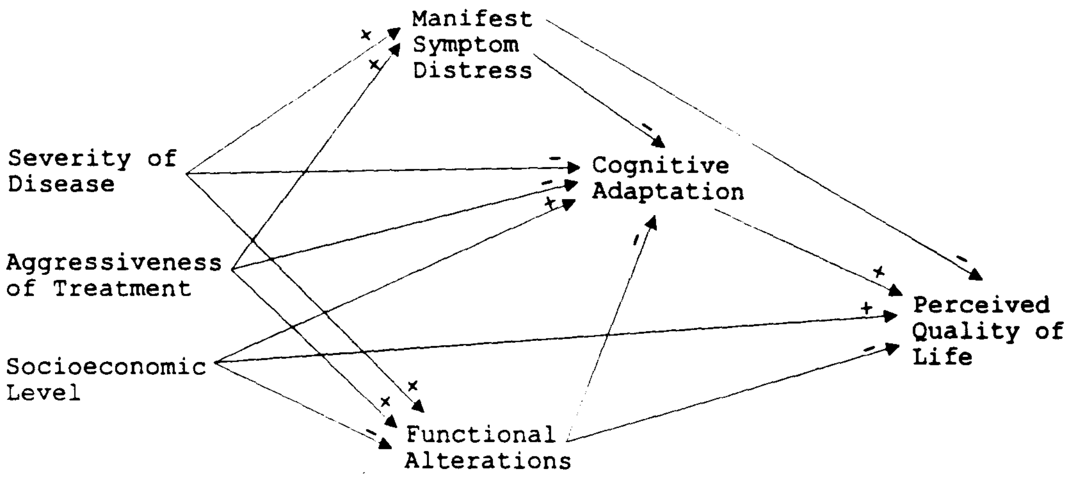


Padilla & Grant, 1985

APPENDIX D

FIGURE 3

GRAHAM-COWAN MODEL
FOR
PERCEIVED QUALITY OF LIFE IN CHRONIC ILLNESS



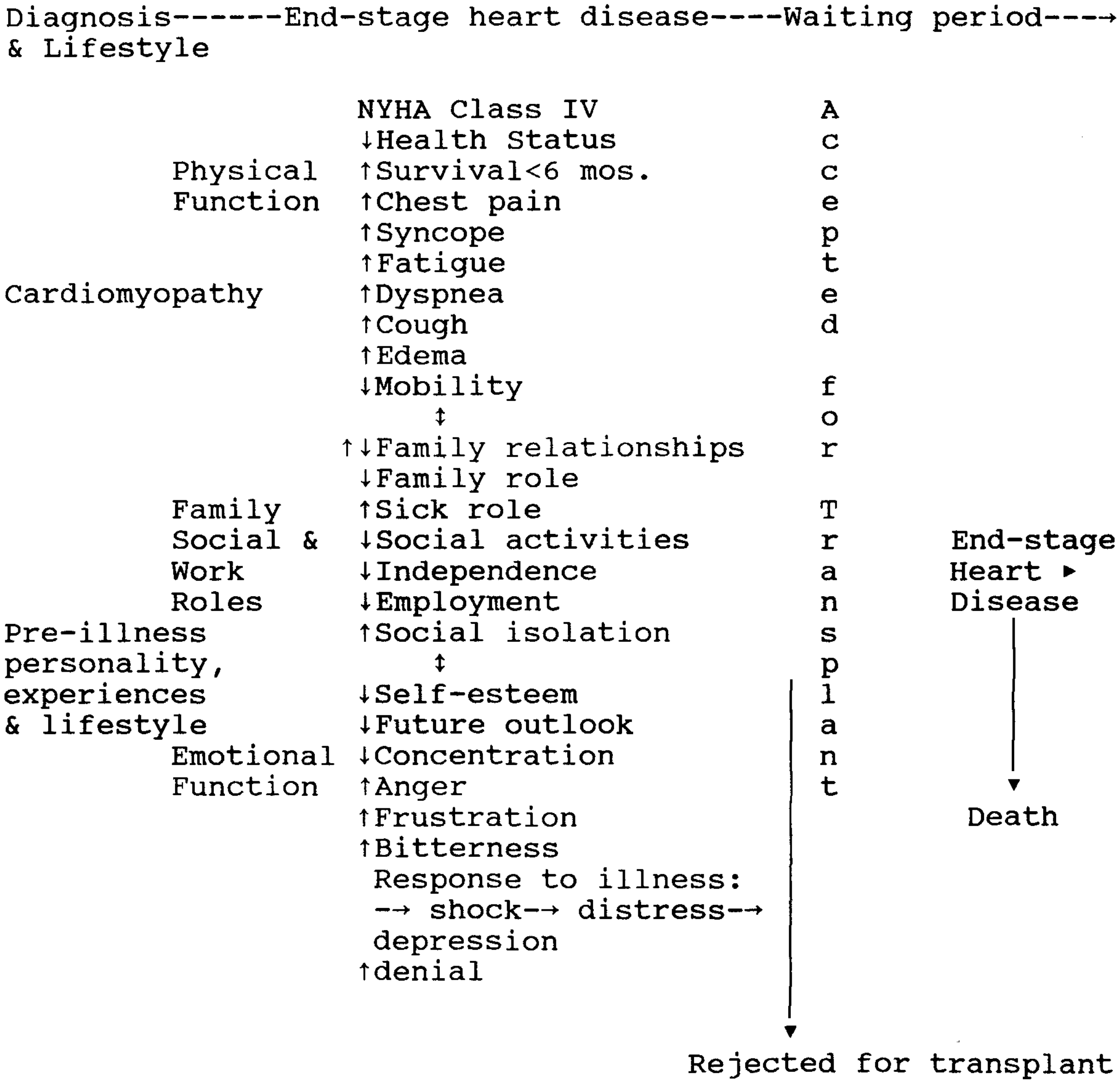
Cowan, Graham, & Cochrane, 1992

APPENDIX E

FIGURE 4

LOUGH QUALITY OF LIFE MODEL

Conceptual Model of Quality of Life from End-Stage Heart Disease to Heart Transplantation



Operation & Hospitalization -----------→ Post-transplant lifestyle----→

Heart Transplant

Physical Function

NYHA Class I
↑Health Status
↑Energy
↑Physical Endurance
↓Cardiac symptoms
↑Immunosuppressive drug side effects & complications
  -Derm. changes
  -Changed phys. appearance
  -Bone problems
  -Hypertension
  -Renal insufficiency
  -Infection
  -Rejection
  -Risk of retx.

↕

Family Social & Work Roles

↑Family focus
↑Social activities
↑Independence
↑↓Employment
↑Financial stress
↑Health insurance risk

↕

Emotional Function

↑Self accomplishment
↑Future outlook
↑Self-esteem
↑↓Concentration
↑↓Mood swings
↑↓Depression

Satisfaction with Quality of Life

Lough (1988)

APPENDIX F

TABLE 11

CARDIOVASCULAR QUALITY OF LIFE

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Heart failure			
Dracup, Walden, Stevenson, & Brecht (1992); "Quality of life in patients with advanced heart failure."	1. Functional capacity (Heart Failure Functional Status Inventory [HFFSI], Six-minute walk); 2. Symptoms NYHA class, HFFSI); 3. Psychosocial perceptions (Multiple Affect Adjective Checklist [MAACL], Psychosocial Adaptation to Illness Scale [PAIS]).	N=134; M:F=111:23; $\bar{X}$ age=50; Length of illness= 84 mos.; $\bar{X}$ EF= 20%; NYHA Class=I-1, II-7, III-50, IV-76.	$\bar{X}$ METs=5.6, 45% reported shortness of breath; 26 (19%) fatigue; 16 (12%) weakness. Pts. mod. anxious and hostile but mod. to sev. depressed. Corr. betw. QOL measures and EF ranged from .02-.12. Six min. walk corr. with self-reported MET (r=-.60, p<.001), and NYHA class (r= -.46, p<.001). MET level, depression and hostility accounted for 43% of variance in total adjustment (p<.001), with depression as 1st variable entered(R^2=.35, p<.001).

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Kubo, et al., (1992); "Beneficial effects of Pimobendan on exercise tolerance and quality of life in patients with heart failure: Results of a multicenter trial."	1. Exercise time (Mod. Naughton TMT); 2. O_2 consumption (Peak VO_2); 3. QOL (Minnesota Living With Heart Failure Questionnaire [MLHF]).	N=198; M:F=155: 43; $\bar{X}$ age=58; Heart failure duration $\bar{X}$=4 yrs.; $\bar{X}$ EF=22%; pts. randomized to placebo, 2.5mg Pimobendan (P), 5 mg P, 10 mg P. P= inotropic agent	Exercise duration increased in 5mg P sig. over placebo (121.6 sec., p<.001), 10 mg. P increased 81.1 sec. (p=.05) over placebo. Peak VO_2 increased sig. over placebo (2.23 ml/kg/min, p<.01). QOL measured by MLHF improved by 8.5 units in 5 mg grp. compared with 1.3 units in placebo grp. (p<.01). No diff. in EF or mortality.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Mayou, Blackwood, Bryant, & Garnham (1991); "Cardiac failure: Symptoms and functional status."	1. Exercise tolerance (mod. Balke TMT); 2. QOL (11 variables likert scale, eg. tiredness, POMS; Semi-structured interview ratings; Diaries).	N=123 pts. grpd. from 3 prior HF studies; M:F=62: 61; Median age=60, 116 NYHA II, 7 NYHA III.	Physical s/s: tiredness and breathlessness. Disturbances in mood assoc. with impaired concentration, irritability and pessimism about future. Ability to perform activities no diff. from before HF but time spent doing them greatly increased. All aspects of leisure and subj. feelings of limitation sig. corr. with ability to exercise (F= 20.36, p<.001).
Baligadoo, et al. (1990); "Effects of enoximone on quality of life."	1. QOL (Visual analogue scale dev. by Baligadoo); 2. Exercise capacity (free walking).	N=10 (double blind, placebo-controlled cross-over; conducted over 3 time periods of 3 wks.).	Dyspnea (E 27.7, P 33.2, p<.01), fatigue (E 12.6, P 14.8, p<.05), NYHA class (E 3.6, P 3.7, p<.05), walking test (E 46 sec., P 30 sec., p<.05), and daily QOL (E 3.6, P 2.7, p<.05) sig. improved on enoximone vs. placebo.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Walden et al. (1989); "Heart transplantation may not improve quality of life for patients with stable heart failure"	1. Psychosocial perceptions (MAACL, PAIS) 3. Functional capacity (HFFSI, 6 minute walk)	24 post-HT patients, 20 CHF patients; $\bar{X}$ age=49 years post-HT, 47 years CHF; $\bar{X}$ LVEF post-HT=62%, CHF=23%.	NS difference in anxiety, depression, and hostility. High PAIS scores in both grps. indicating poor adjustment to illness. CHF grp. had greater impairment of social and leisure activities. $\bar{X}$ METS CHF=5.9, HT=7.3. NS difference in employment status. HT grp. had more unexpected hospital days than CHF.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Tandon et al. (1988); "Assessment of the quality of life of patients with heart failure: A randomized drug trial."	1. QOL (Patient's Self-Rating Scale; Physician's QOL Index; SIP); 2. Physical function (exercise treadmill testing).	N=230; M:F=_196: 84; $\overline{X}$ age= 59; 67% NYHA Class III; Baseline ETT-7.5 min Mod Naughton; randomized symptomatic CHF pts.	Baseline self-rating scores (medians): fatigue=5, SOB=3, sleeplessness=2 (0=no problem, 10=severe problem). Scores increased just prior to trmt. failure. Fatigue=8, SOB=7, sleeplessness=6. SIP did not discriminate between trmt. successes and failures. Corr. between SOB and ETT, r=-.40, p<.01; ETT and sleeplessness, r=-.28, p<.01.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Guyatt, et al. (1988); "A controlled trial of digoxin in congestive heart failure."	1. Exercise tolerance (progressive ergometer exercise test & 6 min. walk) 2. QOL (CHF questionnaire). 3. Heart function (echocardiogram). 4. Heart failure score (computed by combining history, physical exam and radiographic findings).	N=20, M:F= 18:2. $\bar{X}$ age=63; cause of CHF:17= isch. CM, HTN CM=1, IDC=1; NYHA class: I= 2, II=10, III=8; cross-over trial (digoxin & placebo).	Dyspnea improved with active trmt. (p=.04), no sig. diff. in fatigue or emotional func. Fractional shortening % by echo sig. higher in dig. vs. placebo (p=.004). Dig. pts. able to walk 19 meters more than placebo pts. (p=.055). Heart failure score sig. better for dig. grp. vs. placebo grp. (p=.001).

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Rector, Francis, & Cohn (1987); "Patients' self-assessment of their congestive heart failure. Part 1. Patient perceived dysfunction and its poor correlation with maximal exercise tests."	1. Perceived dysfunction (SIP); 2. Exercise tolerance (bicycle ergometer or treadmill test).	N=45 consecutive pts. (87% male); $\bar{X}$ age=59; 49% ischemic CM, 47% idiopathic CM; 96% taking diuretic, 89% digoxin, 76% vasodilators.	SIP and peak O_2 consumption moderately associated (r= -.36, p=.002). Peak O_2 consump. sig. corr. with physical limitations: ambulation (r= -.56, p<.01), sleep and rest (r=-.43, p<.01), home mgmt. (r=-.34, p<.05), and body care & mvmt. (r=-.39, p<.05). Social interaction (r=-.22), alertness (r= -.25), emotional behavior (r= -.25) and communication (r=.03) were not associated. SIP scores sig. lower (better) for women than men (2.5 vs 12.1, p<.001).

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Angina			
Wiklund, Comerford, & Dimenas (1991); "The relationship between exercise tolerance and quality of life in angina pectoris."	1. Type of angina (Angina Pectoris Ques.); 2. Functional class (NYHA); 3. Exercise tolerance (ETT); 4. QOL (Psychological General Well-Being [PGWB] Index, Angina Pectoris QOL Ques., VAS for symptoms, emotions, & life satisfaction, mod. Jenkins sleep dysfunction scale).	N=50, M:F= 42:8; $\bar{X}$ age=59.5; 42=NYHA I, 8=NYHA II; Severity of angina: 0-1 attacks/ wk=14, 2-6 attacks/ wk=25, 1-2 attacks/ day=10, ≥3 attacks/ day =1.	Mod.-sev. complaints in phys. activity, somatic s/s, emotional distress, life sat., genl. health, well-being, anxiety, depressed, self-control and sleep. No corr. betw. subj. measures and max. workload. Sig. corr. betw. angina sev. and well-being (r= -.57, p<.0001). Sig. corr. betw. angina sev. and somatic complaints (r=.54, p<.0001), emotions (r=.39, p=.0007), and phys. activity (r=.47,p=.0005) NS corr. betw. angina sev. and life satis. Sig. corr. betw. ETT and depress. (r= -.36, p=.01), somatic complaints (r= -.38, p=.007), and physical activity (r= -.40, p.004).

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Fletcher, McLoone, & Bulpitt (1988); "Quality of life on angina therapy: A randomized controlled trial of transdermal glyceryl trinitrate against placebo."	1. Chest pain (Rose chest pain ques.and diary cards); 2. QOL (SIP).	N=468; $\bar{X}$ age=60.4 (placebo [P]), 60.5 (active [A]); all pts. crossed-over to A; previous MI: P=48%, A=39%; sig. diff. in SIP @ entry: P=11.5 A= 9.4 ($p<.05$). Higher score= worse QOL.	A & P grps. showed a decline in angina attack rates. When P's were crossed over to A, attack rate decreased further. P had greater improvement in SIP, greatest diff. in social interaction ($p<.01$). Change in SIP reduced when P's crossed over to A. Headaches reported by 23% A and 6% P ($p<.001$).
Myocardial infarction			
Daumer & Miller (1992); "Effects of cardiac rehabilitation on psychosocial functioning and life satisfaction of coronary artery disease clients."	1. Psychosocial status (SIP); 2. QOL (Quality of Life Index [QLI], Ferrans & Powers).	N=47; 21 out-patient rehab. (OR), 26 home rehab. (HR); data collected 6-8 wks. after coronary event.	NS diff. betw. grps. on psychosocial status or QOL measures. Strong corr. betw. QOL and psychosocial measures/ subscales (NS SIP communication, QLI family). Corr. betw. QLI and SIP total scores: $r=.62$, $p\leq.01$.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Tsevat et al. (1991); "Functional status versus utilities in survivors of myocardial infarction."	1. Chest pain, work status, exercise status (interview); 2. QOL (VAS); 3. Feelings (verbal rating scale and time trade-off); 4. Functional status (Karnofsky, NYHA, Specific Activity Scale).	N=80, M:F= 63:17; interviewed on average 12.7 mos. after MI; NYHA class: I= 62, II= 17, III= 1; $\bar{X}$ age=60.3.	Mean QOL VAS=.68. Mean QOL verbal rating scale=.70. Mean time trade-off=.87. Mod. corr. betw. QOL and time trade-off (r=.45), func. status (r=.44), specific activity (r= -.34) and NYHA class (r=-.33). Strong corr. betw. QOL VAS and QOL verbal rating (r=.93).
Oldridge et al. (1991); "Effects on quality of life with comprehensive rehabilitation after acute myocardial infarction."	1. QOL (Quality of Life After Acute Myocardial Infarction, Time Trade-off, QOL well-being); 2. Exercise tolerance.	N=201 randomized to 99 formal rehab. (R) and 102 conventional comm. care (C); R=88% male, C=90% male; $\bar{X}$ age= 52.9 (R); 52.7 (C); data collected at baseline 2,4,8 and 12 mos.	All QOL and exercise tol. measures improved over 12 mos ($p \leq .001$). Greatest gain betw. baseline and 8 wks. At 8 wks. R had better emotional scores, 110 vs. 98 ($p < .05$); less anxiety, 42 vs. 44 ($p < .05$); and better exercise tolerance, 841 kpm/min vs 819 ($p < .05$). NS diff. betw. grps. at 12 mos.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Packa et al. (1989); "Quality of life of elderly patients enrolled in cardiac rehabilitation."	1. Physical, social and emotional health (McMaster Health Index); 2. QOL (Cantril Self-Anchoring Scale).	N=51 elderly pts. with documented CAD; M:F= 77%:23%; 100% white; $\bar{X}$ age=71; 72% in rehab. program 1-12 mos.	QOL in physical (.82), social (.79) and emotional (.72) domains was satisfactory. QOL rated as 5 pre cardiac rehab. (Cantril; retrospective), 8 at time of interview and projected to be 9 upon completion of program. Physical and social domains sig. corr. (r=.55, p<.05). Physical and social domains sig. corr. with overall QOL measure (r=.38 phys, r=.33 social, p<.05). Age was sig. corr. with physical domain (r=-.21, p<.05).

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Wiklund, Herlitz, & Hjalmarson (1989); "Quality of life five years after myocardial infarction."	1. Demographics, symptoms, readmission (Cardiac Follow-up Quest.); 2. QOL (Nottingham Health Profile).	N=444 pts. enrolled in Metoprolol clinical trial; 77% male; $\bar{X}$ age=67.	58% reported angina 5 yrs. after MI; 7% had CABG surgery. Impaired health most pronounced when compared with normal population: energy (27% v 15%), sleep (22% v 16%), mobility (13% v 6%), sex life (26% v 15%), hobbies (22% v 15%) and holidays (21% v 12%). Higher score=more impaired. Decreased QOL sig. related to gender (F affected more by s/s than M).

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Hlatky, et al. (1986); "Medical, psychological and social correlates of work disability among men with coronary artery disease."	1. Clinical factors (symptom severity, prior MI, coronary anatomy, LVEF). 2. Psychosocial factors (MMPI, Zung Depression and Anxiety Scales, Jenkins Activity Survey, measures of education and social support).	N=814 men, 610 nondisabled (ND), 204 disabled (D); $\bar{X}$ age=49 both grps.	ND were better educated ($\bar{X}$=13 vs. 10 yrs. ed., p<.0001), had fewer previous MIs (.55 vs. 1.05, p<.00001), had higher CHF class (p<.00001), lower myocardial damage index (p<.00001), higher LVEFs (51% vs. 46%, p<.00001), less PV disease (p<.05), and fewer diseased vessels (p<.04). D men had higher anxiety (p<.001), more depression (p<.001), scored higher on MMPI hypochondriasis (HC) scale (p<.001), had less ego strength (p=.0001), lessened work attitude (p=.0005) and less social support(p=.02). Predictors of work disability were: low education, hx. of MI, depression, and high HC.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Olsson, Lubsen, vanEs, & Rehnqvist (1986); "Quality of life after myocardial infarction: effect of long term metoprolol on mortality and morbidity."	1. Survival; 2. # days in 7 different health states: 1) dead, 2) atheroscl complication, 3) NYHA IV, no ath. comp. 4) NYHA III, no ath. comp. 5) NYHA II, no ath. comp. 6) NYHA I + side effects, no ath. comp. 7) NYHA I, no ath. comp., no side effects.	N=301 randomized to 154 Metoprolol 100 mg BID (M) and 147 placebo (P); $\bar{X}$ age =59.2 (P), 60.1 (M); 83% men (P), 78% (M).	Max. attainable days alive=1095; M attained 992 days, P 964 days. M grp. spent 278 days at optimal function compared to 176 days for P. Time spent with serious complications= 56 days < for M vs. P. Overall diff. betw. grps. were stat. sig. (p=.03).

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Wiklund, Sanne, Vedin, & Wilhelmsson (1984); "Psychosocial outcome one year after a first myocardial infarction."	1. Emotional adjustment; 2. Neurotic adjustment; 3. Sexual adjustment; 4. Psychosocial adjustment (quest. used for above not delineated)	N=177 men 2 mos. after 1st MI; Median age=54; reference grp. of random 175 men enrolled in a population study; pts. studied at 2 mos. and 1 yr. post-MI	Sig. lessening of fatigue, depression, restlessness, unenterpriseness and sensitivity from 2 mos. to 1 yr. ($p \leq .01$). Sig. more psychosom. symp. in MI grp. at 1 yr. than ref. grp. ($p \leq .001$). Sig. increase in stress, remembering and gastritis from 2 mos. to 1 yr. after MI ($p \leq .01$). 62% were satisfied with life, 29% neither satisfied or dissatisfied, and 9% dissatisfied. Life satisfaction more positive at 1 yr. vs. 2 mos. ($p \leq .01$).

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Mayou, Foster, & Williamson (1978b); "Psycho-social adjustment in patients one year after myocardial infarction."	1. Physical symptoms; 2. Mental state; 3. Social activities; 4. Satisfaction with social activities (data obtained through interview, any instrumentation, if used, not defined).	N=100 pts. suffering 1st MI interviewed during hospitalization, 2 mos. and 1 yr. after discharge; age betw. 29 and 69 yrs.	Two-thirds of sample c/o at least 1 symptom persisting 1 yr. after MI (breathlessness chest pain or other symptoms). Psychological distress at 1 yr.: 36% nil or slight, 32% mod., 32% marked (predom. anxiety and depression). 60% working prior to MI were working at 12 wks. 66% reported a decrease in leisure activity. 55.7% reported no change in marriage, 24.1% had improved marriages and 19.3% reported a decline in their marriage at 1 yr. Sig. corr. betw. mental state and phys. symp., coping, marriage, leisure and work (P<.05).

APPENDIX G

TABLE 12

FAMILY QUALITY OF LIFE

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Artinian & Hayes (1992); "Factors related to spouses' quality of life 1 year after coronary artery bypass graft surgery."	1. QOL (Quality of Life Index-Ferrans & Powers); 2. Social support (NSSQ); 3. Income 4. Health (Cantril's self-anchoring ladder). 5. Objective physical health (physical ailment checklist).	N=39 women; $\bar{X}$ age=56; 98% white; $\bar{X}$ married 33 years; 61% not employed, 20% part-time employed, 16% full-time employed.	Mod. QOL 1 yr. after CABG. Family subscale sig. higher than others; health/ functioning sig. lower than others. Social support was mod. Social supp. was sig. higher 48 hrs. after CABG which was sig. higher than 6 wks. after CABG. Pts. health was good and own health slightly better. Sig. r betw. QOL and affirmation support (r=.30, p<.03), physical health (r=.58, p=.001), income (r=.35, p<.015), perception of partners health (r=.41, p<.003), and perception of own health (r=.68, p<.001). Spouse's health and affirmation support accounted for 61% of variance in spousal QOL.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Nolan et al. (1992); "Perceived stress and coping strategies among families of cardiac transplant candidates during the organ waiting period."	1. Family Inventory of Life Events and Changes (FILE); 2. Family Crisis Oriented Personal Scale (FCOPES); 3. Family Perception of the Transplant Experience Scale (FPTES)	N=38 family members, M:F=3:35; X age=44; X waiting time on list=6.5 mos.	53% experiencing moderate stress; 47% experiencing low stress. Used more coping mech. than normative subjs. Coping strategies used frequently: knowing family has strength to solve problems, facing problems head-on, and seeking support from friends. Subjs. appraised pre-transplant experience as positive. As the perception of the heart transplant experience became more negative, family stress increased (r=.38, p=.03).

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Beach et al. (1992); "The spouse: A factor in recovery after acute myocardial infarction."	1. Social support (Social Support Index [SSI]); 2. Family stress (FILE); 3. Marital satisfaction (Dyadic Adjustment Scale [DAS]); 4. Sexual comfort (Comfort with Sexual Activity scale); 5. Pts. recovery (Recovery Index).	N=17 spouses, M:F=3:14; $\bar{X}$ age=52; studied prior to discharge (d/c), 3 wks. after d/c, 3 mos. after d/c, and 6 mos. after d/c.	No relationship betw. social support and recovery. Weak, positive relationship betw. spouse and stress (FILE) and recovery @ 3 and 6 mos. (r=.42 and .50). Weak, positive relationship betw. marital satisfaction and the patient's recovery @ 3 mos. (r=.42).

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Artinian (1991); "Stress experience of spouses of patients having coronary artery bypass during hospitalization and 6 weeks after discharge."	1. Stress (FILE, Spouse Stressor Scale [SSS]); 2. Social support (Norbeck Social Support Index [NSSI]); 3. Coping (Coping Response-Moos); 4. Pt. illness (Cantril Self-Anchoring Ladder); 5.Strain (Strain Quest., Role Strain Scale); 6. Marital quality (DAS).	N=86 wives of pts. having 1st CABG surgery; $\bar{X}$ age=56; studied in hospital and @ 6 wks.	Wives report low consistent role strain for T_1 and T_2. T_1=slightly lower marital quality (DAS= 106.9); T_2=sig. lower marital quality (102.13). Spousal stress persists at 6 wks. Women reported average # of family life changes and high social support @ T_1 and T_2. Husband's illness severity perceived as very high at T_1 and sig. less @ T_2. Active coping methods and avoidance methods used more often than normed community sample.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Mathieson, Stam & Scott (1991); "The impact of laryngectomy on the spouse: Who is better off?"	1. Body image; 2. Relationships; 3. Restrictions on patient; 4. Emotions (POMS); 4. QOL (Life satisfaction rating).	N=30 laryngectomy pts. and spouses; $\bar{X}$ age=62; median length of relationship=32 yrs.; $\bar{X}$ yrs. after laryn.=2.9 yrs.	Spouse scored lower than patient: body image of pt. ($p<.001$), relationship with partner ($p<.01$), sexual relationships ($p<.01$) and QOL ($p<.01$). Spouse had sig. more depression ($p=.055$), tension ($p<.05$) and fatigue ($p<.05$). Lifestyle changes (sex relationship and effect on relationships) strongest predictor of QOL (R^2 change=.37, $p<.05$). R^2=.68 with age/sex as step 1, medical information as step 2 and lifestyle changes as step 3.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Bohachick & Anton (1990); "Psychosocial adjustment of patients and spouses to severe cardiomyopathy."	1. Health-care orientation (h/c or.); 2. Work; 3. Home; 4. Sex relationship; 5. Extended family social environment; 6. Psych. distress (PAIS all variables).	N=90 couples; $\bar{X}$ age=50.92 pts., $\bar{X}$ age=27.6 spouses; length of illness=1 mo. to 15 yrs.	Spouses report poorer adj. (higher score) in h/c or.(4.48 vs. 6.86, p<.001), extended fam. relations (2.13 vs. 3.06, p<.03), psych. distress (6.97 vs. 8.39, p<.03) & overall adj.(50.07 vs. 44.64, p<.03). Pts. report sig. lower adj. in vocational environ., (11.31 vs. 6.04, p<.001) & sexual relation. (8.24 vs. 7.26, p<.03). NS diff. in social environ.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Gilliss, Neuhaus, & Hauck (1990); "Improving family functioning after cardiac surgery: A randomized trial."	1. Family function (Family APGAR); 2. Marital satisfaction (Marital satisfaction scale [MAS]); 3. Resources (FIRM) *Intervention study: effect of addl. teaching on family function.	N=67 couples; pts. M:F= 54:24; studied @ 3 time periods: before d/c, @ 3 mos. and 6 mos.	Family function decreased from baseline to 3 mos. (pts. $p<.009$, SOs $p<.005$). At 6 mos. pts. reported improved family function and SOs did not. Marital sat. increased from T_1 to T_3 for pts. ($p=.05$) and decreased for SOs. Resources for pts. increased consistently and decreased consistently for SOs. NS diff. betw. intervention and control grps.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Buse & Pieper (1990); "Impact of cardiac transplant on the spouses life."	1. Perception of heart transplant life and relationships (Perception of Heart Transplant Questionnaire and DAS-1 item); 2. Stress (Subjective Stress Scale [SSS]);	N=30 post-HT spouses; M:F=4:26; retrospectively answered pre-HT questions; time after HT=67 days to 3 yrs.	Post-HT more positive than pre-HT (p<.001). NS diff. in stress pre vs. post-HT. Highest mean scores while waiting for heart: fear over loss of spouse; learn more about HT; time available for self; life in general; and ability to make future plans. Highest scores post-HT: learn more about HT; availability of support; relationship with family/ friends; independent decision making; and relationship with children/ grandchildren.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Leavitt (1990); "Family recovery after vascular surgery."	1. Family function (Family APGAR); 2. Family resources (FIRM); 3. Family coping (FCOPES); 4. QOL (Qualitative).	N=42, 21 pts. and 21 family care partners; subj. interviewed on admission and 3 mos. after d/c.	Family APGAR lower for fam. partners than pts. (17.8 vs. 15.3, p=.03). Sig. lower score on FCOPES "social support" for fam. vs. pt. (3.0 vs. 2.3, p=.04) and "mobilizing family" scale (3.2 vs. 2.6, p=.03). Fam. partners reported lower QOL and expressed reluctance to ask for help.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Ebbesen, Guyatt, McCartney & Oldridge (1990); "Measuring quality of life in cardiac spouses."	1. QOL (QOL Quest. for Cardiac Spouses [QLSP], RAND Quality of Well-being, Cantril Self-Anchoring Scale, Global well-being question); 2. Depression (Becks Depression Index); 3. Anxiety (State & Trait Anxiety Index); 4. ADLs (Katz Instrumental ADL Index); 5. Marital satisfaction (Marital Satisfaction Index-Locke & Wallace).	N=42 spouses of pts. who had MI 1-2 wks. prior; M:F= 3:39; $\bar{X}$ age= 51.7; studied 1-2 wks. after MI and 8 wks. after MI.	Scale consisted of 2 subscales: emotional function and physical/social. Function improved from T_1 to T_2 for both subscales ($p<.001$). NS diff. betw. male and female responses. By T_2, 59% (N=23) had visited a doctor for headaches, high BP and nonspecific chest pain. Correlations betw. QLSP subscales and other instruments were acceptable.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Voepel-Lewis, Starr, Ketefian, & White (1990); "Stress, coping, and quality of life in family members of kidney transplant recipients."	1. Stress and coping (Kidney Transplant Questionnaire-Ketefian); 2. QOL (2 global rating questions).	N=50 family members; 74% female; $\bar{X}$ age= 47.6; studied 3 wks. to 6 mos. after kidney tx.; reported pre-tx. scores retrospectively obtained.	Primary concerns: longterm side effects of meds.; complications; pain for recipient. Self-controlling and problem solving coping used most. Women used more social supp. & positive reappraisal coping. Mean QOL scores (7-point scale) pre-tx.= 4.5, post-tx.= 5.36, $p<.01$. QOL predicted from total stress & coping score (Pre-tx. $R^2=.19$; post-tx. $R^2=.25$). Total coping score was primary predictor for both equations.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Miller & Wikoff (1989); "Spouses' psychosocial problems, resources, and marital functioning postmyocardial infarction."	1. Compliance (Health Behavior Scale); 2. Role responsibility (Spouse quest.); 3. Marital func. (Marital Function Scale, Marital Responsibility Scale); 4. Anxiety (STAS); 5. Coping (JCS).	N=40 1st time MI pts. and spouses (M:F spouses= 9:31); $\bar{X}$ age spouse=49; $\bar{X}$ age pt.= 53; $\bar{X}$ length of marriage= 23 yrs.; pts. and spouses studied 3 mos. after MI.	Marital function high at T_1 and T_2. Anxiety levels neither high nor low. Coping methods used: confrontive, palliative and emotive. Greater use of emotive coping methods corr. with decreased marital function.
Mishel & Murdaugh (1987); "Family adjustment to heart transplantation: Redesigning the dream."	1. Coping; 2. Adjustment (grounded theory approach).	N=20 family members of HT pts.; 3 grps: 7 pre-HT, 8 during HT hospitalization, 5 post-HT.	Identified 3 stages: 1. Waiting, immersion (freeing self, symbiosis, trading places); 2. Hospital, passage (catharsis, vacillation, awareness); 3. Recovery and negotiation.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Sexton & Munro (1985); "Impact of a husband's chronic illness (COPD) on the spouse's life."	1. Burden (Illness impact form); 2. Stress (SSS); 3. Life satisfaction (Life satisfaction index-A).	N=46 wives of COPD pts. and 30 wives of "normal" husbands with similar demographics.	Biggest problems: pt. condition and symptoms, irritability, loss of freedom. Few outlets to reduce stress. 54% no longer engaged in sex. Wives of COPD pts. reported sig. higher subj. stress ($p=.032$) and lower life satisfaction ($p=.006$). Regression equation (life sat.=DV): subj. stress=28% var.; finances=10% var.; dx. of COPD=7% var.; work status of wife=4% var.
Gilliss (1984); "Reducing family stress during and after coronary artery bypass surgery"	1. Stress (Impact of Event Scale); 2. Family changes related to illness (semi-structured interview)	N=71 couples at time of CABG surgery (61:10 M:F pts.); 41 couples 6 months after surgery; $\overline{X}$ age=59	Spouses reported sig. higher levels of subjective stress over pts. ($p=.001$). Pt. and spouse scores were sig. correlated ($r=.28$, $p=.018$). Role of spouse contributed to higher stress; not gender.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Bedsworth & Molen (1982); "Psychological stress in spouses of patients with myocardial infarction."	1. Stressors 2. Coping; 3. Affect/ emotions (semi-structured interview).	N=20 spouses of MI pts. within 72 hrs. of MI; $\bar{X}$ age=52.	Most frequently cited threats: loss of mate, loss of healthy mate; recurrence of MI. Each spouse reported feeling anxious.
Stern & Pascale (1979); "Psychosocial adaptation post-myocardial infarction: The spouse's dilemma."	1. Depression (Zung Self Rating Depression Scale); 2. Anxiety (Taylor Manifest Anxiety Scale); 3. Adjustment (Interview).	N=38 spouses of recent MI pts. (assessed at time of MI and 6 mos. later); no further demographics.	26% (N=10) were either anxious or depressed at initial interview. At 6 mos., only 4 continued to be symptomatic. Symptomatic spouses had more marital difficulty ($p<.02$), friction ($p<.01$ and distress ($p<.05$). Spouses were preoccupied with husbands illness and family equilibrium was unalterably disturbed.

AUTHOR/TITLE	VARIABLES/ INSTRUMENTS	SAMPLE	FINDINGS
Mayou, Foster & Williamson (1978a); "Psychological and social effects of MI on wives."	1. Psychological effects; 2. Social effects (structured interview).	N=82 wives (no demographics); studied while husband in hospital, at 2 mos. and 1 yr.	While husbands in hospital, 95% of wives reported anxiety; 38% were mod-sev. distressed (crying, sleep and appetite disturbances). One year later, wives still had psychological distress. 40% of wives c/o ill health after MI. Marriages were described as being a difficult year. Least distressed wives enjoyed jobs, maintained leisure activities, satisfactory marriages. Wives reaction was not related to husbands condition, anxieties or restricted social life.

APPENDIX H

QUESTIONNAIRE BOOKLET

Study #___________
Date______________
Site:
___ LUMC
___ HVAH
___ UABMC

HEART TRANSPLANT SPOUSES QUALITY OF LIFE STUDY

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Spouse Transplant Stressor Scale

The following questionnaire lists typical stressors experienced by spouses of transplant candidates during the wait for a heart. Please rate how stressful each factor has been for you by circling the appropriate response.

0 = not stressful at all
1 = slightly stressful
2 = fairly stressful
3 = very stressful
NA = not applicable (means that you have not experienced this)

Please note the difference between NA and #0. If you have not experienced a particular thing, then you would mark NA. If you have experienced it, but have not found it stressful at all, then you would mark #0.

	Not Stressful at All	Slightly Stressful	Fairly Stressful	Very Stressful	Not Applicable
1. Waiting for the transplant	0	1	2	3	NA
2. Not knowing if a heart will come along	0	1	2	3	NA
3. Feeling guilty about my spouse getting someone else's heart	0	1	2	3	NA
4. Feeling angry that more people do not donate organs	0	1	2	3	NA
5. Worrying that the new heart might not work	0	1	2	3	NA
6. Afraid that my spouse might die	0	1	2	3	NA
7. Limited finances due to my spouse's illness	0	1	2	3	NA
8. Lack of information about the transplant process	0	1	2	3	NA
9. Having to communicate about my spouse's health problems with many different doctors and nurses	0	1	2	3	NA
10. Having my questions answered by the medical and/or nursing staff	0	1	2	3	NA

	Not Stressful at All	Slightly Stressful	Fairly Stressful	Very Stressful	Not Applicable
11. Not being kept informed by the staff of my spouse's condition	0	1	2	3	NA
12. Not understanding the information given by staff about my spouse's condition	0	1	2	3	NA
13. Not knowing <u>when</u> the transplant will take place	0	1	2	3	NA
14. Not knowing <u>if</u> the transplant will take place	0	1	2	3	NA
15. Feeling that no one is concerned about <u>my</u> health	0	1	2	3	NA
16. Not being able to talk about my fears and concerns because I have to be the strong one	0	1	2	3	NA
17. Not knowing specific facts about my spouse's condition	0	1	2	3	NA
18. Worrying if medical personnel will take good care of my spouse while he/she is in the hospital	0	1	2	3	NA
19. Not having time for myself	0	1	2	3	NA
20. Afraid to take time for myself because of what others would think/say	0	1	2	3	NA
21. Not being able to plan for the future	0	1	2	3	NA
22. Not being able to take vacations because of my spouse's illness	0	1	2	3	NA
23. Not being able to sleep well	0	1	2	3	NA
24. Needing to take on new responsibilities because of my spouse's illness	0	1	2	3	NA
25. Having to help my spouse take medications	0	1	2	3	NA
26. Having to help my spouse limit his/her fluid intake	0	1	2	3	NA
27. Decline in my social life because of my spouse's illness	0	1	2	3	NA
28. Not having control over my life	0	1	2	3	NA
29. Needing to rely on others	0	1	2	3	NA

	Not Stressful at All	Slightly Stressful	Fairly Stressful	Very Stressful	Not Applicable
30. Understanding my spouse's feelings while awaiting a transplant	0	1	2	3	NA
31. Spouse relying on me more than before	0	1	2	3	NA
32. Others relying on me more than before	0	1	2	3	NA
33. Having to get a job because of my spouse's illness	0	1	2	3	NA
34. Losing my job	0	1	2	3	NA
35. Not being able to do my job as well as before because of my spouse's illness	0	1	2	3	NA
36. Having to take time from my job because of my spouse's illness	0	1	2	3	NA
37. My alcohol and/or drug use	0	1	2	3	NA
38. My spouse's alcohol and/or drug use	0	1	2	3	NA
39. Frequently having to take my spouse to the hospital/doctor's office/clinic	0	1	2	3	NA
40. Having to make changes in my lifestyle due to my spouse's illness	0	1	2	3	NA
41. Having to prepare a special diet for my spouse	0	1	2	3	NA
42. Worrying about paying medical bills	0	1	2	3	NA
43. Worrying about whether our medical insurance will cover the costs associated with transplant	0	1	2	3	NA
44. Worrying about paying bills in general	0	1	2	3	NA
45. Change in sexual activity	0	1	2	3	NA
46. Fear of having sex because of my spouse's illness	0	1	2	3	NA
47. Less (or no) sex in my life	0	1	2	3	NA
48. Less (or no) affection in my life	0	1	2	3	NA
49. Increased conflict in my family due to my spouse's illness	0	1	2	3	NA

	Not Stressful at All	Slightly Stressful	Fairly Stressful	Very Stressful	Not Applicable
50. Having to go on or being on public assistance	0	1	2	3	NA
51. Providing care for a sick or elderly relative (other than my spouse)	0	1	2	3	NA
52. Adjusting to my spouse's illness	0	1	2	3	NA
53. Difficulty arranging care for dependent relatives	0	1	2	3	NA
54. Close friend/family member recently died	0	1	2	3	NA
55. Worrying that the transplant might change my spouse in some way	0	1	2	3	NA
56. Worrying about the effect of surgery on my spouse's physical appearance	0	1	2	3	NA
57. Worrying about my children having heart disease some day	0	1	2	3	NA
58. Having to do things slower because my spouse cannot keep up	0	1	2	3	NA
59. Feeling that there is no hope for my spouse	0	1	2	3	NA
60. Protecting my spouse from everyday problems	0	1	2	3	NA
61. Feeling that I have no one to protect me	0	1	2	3	NA

If there are other things that are not listed above that have caused you stress while your spouse has been waiting for a transplant, would you please list these things below and then rate how stressful each factor has been for you.

62.	1	2	3	
63.	1	2	3	
64.	1	2	3	

FIRM

FAMILY INVENTORY OF RESOURCES FOR MANAGEMENT

Hamilton I. McCubbin Joan K. Comeau Jo A. Harkins

Purpose:

The FIRM was developed to record what social, psychological, community and financial resources families believe they have available to them in the management of family life.

Directions:

To complete this inventory you are asked to read the list of **"Family Statements"** one at a time. Family means your immediate family. Then ask yourself: "HOW WELL DOES THIS STATEMENT DESCRIBE MY FAMILY SITUATION?"

Then make your decision by circling one of the following:

0= Not at all -- This statement does not describe our family situation. This does not happen in our family.

1= Minimally -- This statement describes our family only slightly. Our family is like this <u>once</u> in a while.

2= Moderately -- This statement describes our family situation fairly well. Our family is like this <u>some</u> of the time.

3= Very well -- This statement describes our family very accurately. Our family is like this <u>most</u> of the time.

Statement Describes Our Family

	Not at All	Minimally	Moderately	Very Well
1. We have money coming in from our investments (such as rental property, stocks, bonds, etc.)	0	1	2	3
2. Being physically tired much of the time is a problem in our family.	0	1	2	3
3. We have to nag each other to get things done.	0	1	2	3
4. We do not plan too far ahead because many things turn out to be a matter of good or bad luck anyway	0	1	2	3
5. Our family is as well adjusted as any family in this world can be	0	1	2	3
6. Having only one person in the family earning money is (or would be) a problem in our family	0	1	2	3
7. It seems that members of our family take each other for granted	0	1	2	3
8. Sometimes we feel we don't have enough control over the direction our lives are taking	0	1	2	3
9. Certain members of our family do all the giving, while others do all the taking	0	1	2	3
10. We depend almost entirely upon financial support from welfare or other public assistance programs	0	1	2	3
11. We seem to put off making decisions	0	1	2	3
12. Family members understand each other completely	0	1	2	3
13. Our family is under a lot of emotional stress	0	1	2	3
14. Many things seem to interfere with family members being able to share concerns	0	1	2	3
15. Most of the money decisions are made by only one person in our family	0	1	2	3
16. There are times when family members do things that make other members unhappy	0	1	2	3
17. It seems that we have more illness (colds, flu, etc.) in our family than other people do	0	1	2	3
18. In our family some members have many responsibilities while others don't have enough	0	1	2	3

Statement Describes Our Family

	Not at All	Minimally	Moderately	Very Well
19. No one could be happier than our family when we are together	0	1	2	3
20. It is upsetting to our family when things don't work out as planned	0	1	2	3
21. We depend almost entirely on income from alimony and/or child support	0	1	2	3
22. Being sad or "down" is a problem in our family	0	1	2	3
23. It is hard to get family members to cooperate with each other	0	1	2	3
24. If our family has any faults, we are not aware of them	0	1	2	3
25. We depend almost entirely on social security retirement income	0	1	2	3
26. Many times we feel we have little influence over things that happen to us	0	1	2	3
27. We have the same problems over and over - we don't seem to learn from past mistakes	0	1	2	3
28. One or more working members of our family are currently unemployed	0	1	2	3
29. There are things at home we need to do that we don't seem to get done	0	1	2	3
30. We feel our family is a perfect success	0	1	2	3
31. We own land or property besides our place of residence	0	1	2	3
32. We seem to be so involved with work and/or school activities that we don't spend enough time together as a family	0	1	2	3
33. We own (or are buying) a home (single family, condominium, townhouse, etc.)	0	1	2	3
34. There are times when we do not feel a great deal of love and affection for each other	0	1	2	3
35. If a close relative were having financial problems, we feel we could afford to help them out	0	1	2	3
36. Friends seem to enjoy coming to our house for visits	0	1	2	3

	Statement Describes Our Family			
	Not at All	Minimally	Moderately	Very Well
37. We feel we have a good retirement income program	0	1	2	3
38. When we make plans, we are almost certain we can make them work	0	1	2	3
39. In our family we understand what help we can expect from each other	0	1	2	3
40. We seem to have little or no problem paying our bills on time	0	1	2	3
41. Our relatives seem to take from us, but give little in return	0	1	2	3
42. We would have no problem getting a loan at a bank if we wanted one	0	1	2	3
43. We feel we have enough money on hand to cover small unexpected expenses (under $100)	0	1	2	3
44. When we face a problem, we look at the good and bad of each possible solution	0	1	2	3
45. The member(s) who earn our family income seem to have good employee benefits (such as paid insurance, stocks, car, education, etc.)	0	1	2	3
46. No matter what happens to us, we try to look at the bright side of things	0	1	2	3
47. We feel we are able to go out to eat occasionally without hurting our budget	0	1	2	3
48. We try to keep in touch with our relatives as much as possible	0	1	2	3
49. It seems that we need more life insurance than we have	0	1	2	3
50. In our family it is okay for members to show our positive feelings about each other	0	1	2	3
51. We feel we are able to make financial contributions to a good cause (needy people, church, etc.)	0	1	2	3
52. We seem to be happier with our lives than many families we know	0	1	2	3
53. It is okay for family members to express sadness by crying, even in front of others	0	1	2	3

Statement Describes Our Family

	Not at All	Minimally	Moderately	Very Well
54. When we need something that can't be postponed, we have money in savings to cover it	0	1	2	3
55. We discuss our decisions with other family members before carrying them out	0	1	2	3
56. Our relative(s) are willing to listen to our problems	0	1	2	3
57. We worry about how we would cover a large unexpected bill (for home, auto repairs etc. over $100)	0	1	2	3
58. We get great satisfaction when we can help one another in our family	0	1	2	3
59. In our family we feel it is important to save for the future	0	1	2	3
60. The working members of our family seem to be respected by their co-workers	0	1	2	3
61. We have written checks knowing there wasn't enough money in the account to cover it	0	1	2	3
62. The members of our family respect one another	0	1	2	3
63. We save our extra spending money for special things	0	1	2	3
64. We feel confident that if our main breadwinner lost his/her job, (s)he could find another one	0	1	2	3
65. Members of our family are encouraged to have their own interests and abilities	0	1	2	3
66. Our relatives do and say things to make us feel appreciated	0	1	2	3
67. The members of our family are known to be good citizens and neighbors	0	1	2	3
68. We make an effort to help our relatives when we can	0	1	2	3
69. We feel we are financially better off now than we were 5 years ago	0	1	2	3

PLEASE check all 69 items to be sure you have circled a number for each one. THIS IS IMPORTANT.

Study # _______

JALOWIEC COPING SCALE

This questionnaire is about how you cope with stress and tension, and what you do to handle stressful situations. In particular, I am interested in how you have coped with the stress of:

your spouse waiting for a heart transplant

This questionnaire lists many different ways of coping with stress. Some people use a lot of different coping methods; some people use only a few.

You will be asked two questions about each different way of coping with stress:

Part A

How often have you used that coping method to handle the stress listed above?

For each coping method listed, circle one number in Part A to show how often you have used that method to cope with the stress listed above. The meaning of the numbers in Part A is as follows:

0 = never used
1 = seldom used
2 = sometimes used
3 = often used

Part B

If you have used that coping method, how helpful was it in dealing with that stress?

For each coping method that you have used, circle a number in Part B to show how helpful that method was in coping with the stress listed above. The meaning of the numbers in Part B is as follows:

0 = not helpful
1 = slightly helpful
2 = fairly helpful
3 = very helpful

If you did not use a particular coping method, then do not circle any number in Part B for that coping method.

COPING METHODS	Part A How often have you used each coping method?				Part B If you have used that coping method, how helpful was it?			
	Never Used	**Seldom Used**	**Sometimes Used**	**Often Used**	**Not Helpful**	**Slightly Helpful**	**Fairly Helpful**	**Very Helpful**
1. Worried about the problem	0	1	2	3	0	1	2	3
2. Hoped that things would get better	0	1	2	3	0	1	2	3
3. Ate or smoked more than usual	0	1	2	3	0	1	2	3
4. Thought out different ways to handle the situation	0	1	2	3	0	1	2	3
5. Told yourself that things could be much worse	0	1	2	3	0	1	2	3
6. Exercised or did some physical activity	0	1	2	3	0	1	2	3
7. Tried to get away from the problem for a while	0	1	2	3	0	1	2	3
8. Got mad and let off steam	0	1	2	3	0	1	2	3
9. Expected the worst that could happen	0	1	2	3	0	1	2	3
10. Tried to put the problem out of your mind and think of something else	0	1	2	3	0	1	2	3
11. Talked the problem over with family or friends	0	1	2	3	0	1	2	3
12. Accepted the situation because very little could be done	0	1	2	3	0	1	2	3
13. Tried to look at the problem objectively and see all sides	0	1	2	3	0	1	2	3
14. Daydreamed about a better life	0	1	2	3	0	1	2	3
15. Talked the problem over with a professional person (such as a doctor, nurse, minister, teacher, counselor)	0	1	2	3	0	1	2	3
16. Tried to keep the situation under control	0	1	2	3	0	1	2	3
17. Prayed or put your trust in God	0	1	2	3	0	1	2	3
18. Tried to get out of the situation	0	1	2	3	0	1	2	3
19. Kept your feelings to yourself	0	1	2	3	0	1	2	3
20. Told yourself that the problem was someone else's fault	0	1	2	3	0	1	2	3
21. Waited to see what would happen	0	1	2	3	0	1	2	3
22. Wanted to be alone to think things out	0	1	2	3	0	1	2	3
23. Resigned yourself to the situation because things looked hopeless	0	1	2	3	0	1	2	3

COPING METHODS	Part A How often have you used each coping method?				Part B If you have used that coping method, how helpful was it?			
	Never Used	Seldom Used	Sometimes Used	Often Used	Not Helpful	Slightly Helpful	Fairly Helpful	Very Helpful
24. Took out your tensions on someone else	0	1	2	3	0	1	2	3
25. Tried to change the situation	0	1	2	3	0	1	2	3
26. Used relaxation techniques	0	1	2	3	0	1	2	3
27. Tried to find out more about the problem	0	1	2	3	0	1	2	3
28. Slept more than usual	0	1	2	3	0	1	2	3
29. Tried to handle things one step at a time	0	1	2	3	0	1	2	3
30. Tried to keep your life as normal as possible and not let the problem interfere	0	1	2	3	0	1	2	3
31. Thought about how you had handled other problems in the past	0	1	2	3	0	1	2	3
32. Told yourself not to worry because everything would work out fine	0	1	2	3	0	1	2	3
33. Tried to work out a compromise	0	1	2	3	0	1	2	3
34. Took a drink to make yourself feel better	0	1	2	3	0	1	2	3
35. Let time take care of the problem	0	1	2	3	0	1	2	3
36. Tried to distract yourself by doing something that you enjoy	0	1	2	3	0	1	2	3
37. Told yourself that you could handle anything no matter how hard	0	1	2	3	0	1	2	3
38. Set up a plan of action	0	1	2	3	0	1	2	3
39. Tried to keep a sense of humor	0	1	2	3	0	1	2	3
40. Put off facing up to the problem	0	1	2	3	0	1	2	3
41. Tried to keep your feelings under control	0	1	2	3	0	1	2	3
42. Talked the problem over with someone who had been in a similar situation	0	1	2	3	0	1	2	3
43. Practiced in your mind what had to be done	0	1	2	3	0	1	2	3
44. Tried to keep busy	0	1	2	3	0	1	2	3
45. Learned something new in order to deal with the problem	0	1	2	3	0	1	2	3
46. Did something impulsive or risky that you would not usually do	0	1	2	3	0	1	2	3

COPING METHODS	Part A How often have you used each coping method? Never Used	 Seldom Used	 Sometimes Used	 Often Used	Part B If you have used that coping method, how helpful was it? Not Helpful	 Slightly Helpful	 Fairly Helpful	 Very Helpful
47. Thought about the good things in your life	0	1	2	3	0	1	2	3
48. Tried to ignore or avoid the problem	0	1	2	3	0	1	2	3
49. Compared yourself with other people who were in the same situation	0	1	2	3	0	1	2	3
50. Tried to think positively	0	1	2	3	0	1	2	3
51. Blamed yourself for getting into such a situation	0	1	2	3	0	1	2	3
52. Preferred to work things out yourself	0	1	2	3	0	1	2	3
53. Took medications to reduce tension	0	1	2	3	0	1	2	3
54. Tried to see the good side of the situation	0	1	2	3	0	1	2	3
55. Told yourself that this problem was really not that important	0	1	2	3	0	1	2	3
56. Avoided being with people	0	1	2	3	0	1	2	3
57. Tried to improve yourself in some way so you could handle the situation better	0	1	2	3	0	1	2	3
58. Wished that the problem would go away	0	1	2	3	0	1	2	3
59. Depended on others to help you out	0	1	2	3	0	1	2	3
60. Told yourself that you were just having some bad luck	0	1	2	3	0	1	2	3

If there are any other things you did to handle the stress mentioned at the beginning, that are not on this list, please write those coping methods in the spaces below. Then circle how often you have used each coping method, and how helpful each coping method has been.

61.		1	2	3	0	1	2	3
62.		1	2	3	0	1	2	3
63.		1	2	3	0	1	2	3

Revised 7/90

Ferrans and Powers
QUALITY OF LIFE INDEX

Part I. For each of the following, please choose the answer that best describes **how satisfied** you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Your health?	1	2	3	4	5	6
2. The health care you are receiving?	1	2	3	4	5	6
3. The amount of pain that you have?	1	2	3	4	5	6
4. The amount of energy you have for everyday activities?	1	2	3	4	5	6
5. Your physical independence?	1	2	3	4	5	6
6. The amount of control you have over your life?	1	2	3	4	5	6
7. Your potential to live a long time?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your relationship with your spouse/significant other?	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from others?	1	2	3	4	5	6
15. Your ability to meet family responsibilities?	1	2	3	4	5	6
16. Your usefulness to others?	1	2	3	4	5	6

(Please Go To Next Page)

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
17. The amount of stress or worries in your life?	1	2	3	4	5	6
18. Your home?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your standard of living?	1	2	3	4	5	6
21. Your job?	1	2	3	4	5	6
22. Not having a job?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Your financial independence?	1	2	3	4	5	6
25. Your leisure time activities?	1	2	3	4	5	6
26. Your ability to travel on vacations?	1	2	3	4	5	6
27. Your potential for a happy old age/retirement?	1	2	3	4	5	6
28. Your peace of mind?	1	2	3	4	5	6
29. Your personal faith in God?	1	2	3	4	5	6
30. Your achievment of personal goals?	1	2	3	4	5	6
31. Your happiness in general?	1	2	3	4	5	6
32. Your life in general?	1	2	3	4	5	6
33. Your personal appearance?	1	2	3	4	5	6
34. Yourself in general?	1	2	3	4	5	6

(Please Go To Next Page)

Part II. For each of the following, please choose the answer that best describes **how important** that area of life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Your health?	1	2	3	4	5	6
2. Health care?	1	2	3	4	5	6
3. Being completely free of pain?	1	2	3	4	5	6
4. Having enough energy for everyday activities?	1	2	3	4	5	6
5. Your physical independence?	1	2	3	4	5	6
6. Having control over your life?	1	2	3	4	5	6
7. Living a long time?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your relationship with your spouse/significant other?	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from others?	1	2	3	4	5	6
15. Meeting family responsibilities?	1	2	3	4	5	6
16. Being useful to others?	1	2	3	4	5	6
17. Having a reasonable amount of stress or worries?	1	2	3	4	5	6
18. Your home?	1	2	3	4	5	6

(Please Go To Next Page)

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
19. Your neighborhood?	1	2	3	4	5	6
20. A good standard of living?	1	2	3	4	5	6
21. Your job?	1	2	3	4	5	6
22. To have a job?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Your financial independence?	1	2	3	4	5	6
25. Leisure time activities?	1	2	3	4	5	6
26. The ability to travel on vacations?	1	2	3	4	5	6
27. Having a happy old age/retirement?	1	2	3	4	5	6
28. Peace of mind?	1	2	3	4	5	6
29. Your personal faith in God?	1	2	3	4	5	6
30. Achieving your personal goals?	1	2	3	4	5	6
31. Your happiness in general?	1	2	3	4	5	6
32. Being satisfied with life?	1	2	3	4	5	6
33. Your personal appearance?	1	2	3	4	5	6
34. Are you to yourself?	1	2	3	4	5	6

Rating Questions

1. Please rate the amount of stress you feel you have been under while your spouse has been waiting for a heart transplant. Please circle a number from 1 to 10, with 1 meaning you have been under very little stress, and 10 meaning that you have been under very much stress.

1 2 3 4 5 6 7 8 9 10

Very little stress ______ Very much stress

2. Please rate your health at the present time. Please circle a number from 1 to 10, with 1 meaning that your health is very poor, and 10 meaning that your health is very good.

1 2 3 4 5 6 7 8 9 10

Very poor health ______ Very good health

3. Please rate how well you feel that you have been coping with your spouse being on the heart transplant waiting list. Please circle a number from 1 to 10, with 1 meaning that you you have been coping very poorly, and 10 meaning that you have been coping very well.

1 2 3 4 5 6 7 8 9 10

Coping very poorly ______ Coping very well

4. How would you rate your quality of life since your spouse has been on the heart transplant waiting list? Please circle a number from 1 to 10, with 1 meaning that your quality of life has been very poor, and 10 meaning that your quality of life has been very good.

1 2 3 4 5 6 7 8 9 10

Very poor quality of life ______ Very good quality of life

5. Please rate your spouse's health at the present time. Please circle a number from 1 to 10, with 1 meaning your spouse's health is very poor, and 10 meaning your spouse's health is very good.

1 2 3 4 5 6 7 8 9 10

Very poor health ______ Very good health

6. Please rate the overall impact of the transplant experience on your life. Please circle a number from -5 to +5, with -5 meaning a very negative impact, +5 meaning a very positive impact, and 0 meaning no impact at all.

-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

Very negative impact ______ No impact ______ Very positive impact

Demographic Information

Please complete the following information.

Your Age: _____

Gender: ___Female ___Male

Race: ____ Caucasian
____ African American
____ Oriental
____ Middle-eastern
____ Other (Please specify____________________________)

Number of years of education: _______

Income:
(total family income,
before taxes)

_____ Below $10,000/year
_____ $10,000-29,999/year
_____ $30,000-49,999/year
_____ $50,000-69,999/year
_____ $70,000-89,999/year
_____ $90,000-109,999/year
_____ $110,000-129,999/year
_____ $130,000-149,999/year
_____ $150,000/year or more

Do you have medical insurance for yourself? __ Yes __ No

Is this your ___ first, ___ second, or ___ third marriage?

Length of this marriage: ____________ years

Number of children: ____________

Ages of children: ____________
____
____

Number of children dependent on you and your spouse for financial support: ______

Number of other people dependent on you and your spouse for financial support: ______

Your Occupation: ____

Hours currently worked per week outside the home: ______________

Is your spouse currently in the hospital? ___Yes ___No

Today's date: _______________

Please list any health problems you have now:

____

____

____

____

____

____

____

Comments:

____

____

____

____

____

____

____

Thank-you for taking the time to complete this booklet.

APPENDIX I

INSTRUMENT PERMISSION FORMS

UNIVERSITY OF
WISCONSIN
MADISON

April 5, 1993

Eileen Collins
Department of Veterans Affairs
504 Marina Street
Mt. Prospect, IL 60056

Dear Ms. Collins:

I am pleased to give you my permission to use the **FIRM: Family Inventory of Resources for Management** (McCubbin, H., Comeau, J. & Harkins, J.) instrument. We have a policy to charge $5.00 (one time charge only) *per instrument* to individuals who seek permission. We apologize for this necessity. We also ask that you please fill out the enclosed abstract form and return it to this office.

The manual, **Family Assessment Inventories for Research and Practice, Second Edition**, should be cited when using the instrument. The publication was printed at the University of Wisconsin-Madison in 1991 and edited by Hamilton I. McCubbin and Anne I. Thompson. A brochure is enclosed.

A sample copy of the instrument is enclosed. Additional copies can be obtained at this address for 10 cents each. When large quantities are requested, the cost of postage is also added to the order.

If I could be of any further assistance to you, please let me know.

Sincerely,

Hamilton I. McCubbin
Dean

HIM/kme

Enclosures

Office of the Dean
School of Family Resources and Consumer Sciences

1300 Linden Drive Madison, Wisconsin 53706-1575 608/262-4847 FAX: 608/262-5335

UIC The University of Illinois
at Chicago

Department of Medical-Surgical Nursing (M/C 802)
College of Nursing
845 South Damen Avenue, 7th Floor
Chicago, Illinois 60612
(312) 996-7900

October 9, 1991

Ms. Eileen Collins
504 Marina Street
Mt. Prospect, IL 60056

Dear Ms. Collins:

Thank you for your interest in the Quality of Life Index (QLI). I have enclosed the generic version of the QLI and the computer program for calculating scores. I also have included a list of the weighted items that are used for each of four subscales: health and functioning, socioeconomic, psychological/spiritual, and family, as well as the computer commands used to calculate the subscale scores. The same steps are used to calculate subscale scores and overall scores.

There is no charge for use of the QLI. You have my permission to use the QLI for your study. In return, I would appreciate it if you would send me all publications of your findings using the QLI. Such reports are extremely important to me.

If I can be of further assistance, please do not hesitate to contact me. I wish you much success with your research.

Sincerely,

Carol Ferrans

Carol Estwing Ferrans, PhD, RN
Assistant Professor

Chicago Peoria Quad-Cities Urbana-Champaign

PERMISSION FOR USE OF JCS

PERMISSION IS HEREBY GRANTED TO

Eileen Collins

TO USE THE JALOWIEC COPING SCALE
IN A STUDY OR PROJECT

Anne Jalowiec

ANNE JALOWIEC, RN, PHD
LOYOLA UNIVERSITY OF CHICAGO

DATE: 11-13-91

APPENDIX J

TABLE 13

SUBSCALES FOR THE SPOUSE TRANSPLANT STRESSOR SCALE

Transplant Stressors

---

1. Waiting for transplant
2. Not knowing if heart will come along
3. Feeling guilty about spouse getting someone else's heart
4. Feeling angry more people do not donate organs
5. Worrying that new heart may not work
6. Afraid spouse might die
8. Lack of information about transplant
9. Communicating with many different doctors and nurses
10. Having my questions answered
11. Not being kept informed of spouse's condition
12. Not understanding information given
13. Not knowing when transplant will take place
14. Not knowing if transplant will take place
17. Not knowing specific facts about spouse's condition
18. Worrying if medical personnel will take care of spouse
30. Understanding spouse's feelings
55. Worrying transplant might change spouse
56. Worrying about effect of surgery on spouse
57. Worrying about children having heart disease
59. Feeling there is no hope for spouse

Socioeconomic Stressors

---

7. Limited finances due to spouse's illness
33. Having to get job because of spouse's illness
34. Losing job
35. Not being about to do job as well as before
36. Having to take time from job because of spouse's illness
42. Worrying about paying medical bills
43. Worrying whether medical insurance will cover cost
44. Worrying about paying bills in general
50. Having to go on public assistance

Responsibility Stressors

---

24. Needing to take on new responsibilities
25. Helping spouse take medication
26. Helping spouse limit fluid intake
31. Spouse relying on me more than before
32. Others relying on me more than before
39. Taking spouse to hospital/clinic/doctor
41. Preparing special diet for spouse
51. Caring for sick or elderly relative
53. Arranging care for sick or elderly relative

Stressors Related to Self

---

15. Feeling no one is concerned about my health
16. Not being able to talk about fears and concerns
19. Not having time for myself
20. Afraid to take time for self
21. Not being able to plan for future
22. Not being able to take vacations
23. Not being able to sleep well
27. Decline in social life
28. Not having control over life
29. Needing to rely on others
37. My alcohol and/or drug abuse
38. My spouse's alcohol/drug abuse
40. Having to change lifestyle due to spouse's illness
45. Change in sexual activity
46. Fear of having sex because of spouse's illness
47. Less (or no) sex in my life
48. Less (or no) affection in my life
49. Increased conflict in my family
52. Adjusting to spouse's illness
54. Close friend/family recently died
58. Having to do thing slower because spouse can't keep up
60. Protecting spouse from everyday problems
61. Feeling I have no one to protect me

APPENDIX K

INTRODUCTORY LETTER

Date

Subject's Name
Street Address
City, State Zip code

Dear Mr./Mrs. ,

I am a Heart Transplant Coordinator for the Loyola University Medical Center and Hines Veterans Affairs Hospital combined heart transplant program. I am also a doctoral student in nursing at Loyola University. Throughout my years as transplant coordinator, I have developed an interest in how heart transplantation affects spouses of potential heart transplant patients. As part of my doctoral work, I have designed a survey to study these issues.

I am asking for your help by completing the attached forms. The forms ask you about the stresses you may or may not have experienced since your spouse has been waiting for a heart; how you have coped with your spouse waiting for a heart; what resources your family has available to help in coping; how you would rate various aspects of your life; and some general questions such as your age, number of members in your family, and your overall health. The forms will take about an hour to complete. A stamped return envelope has been provided for your convenience. In addition, you will be paid $5 for your time and effort in completing the forms and will receive the check within one month of returning the completed booklet.

Your participation in this study is completely voluntary. Your decision to participate or not to participate in this study will not affect the care that you or your spouse receive by the heart transplant team. In addition, your spouse's wait for transplant will not be affected in any way by your decision to participate or not to participate in this study. All information that you provide will be kept completely confidential. Your name will not appear on any of the study forms. You will also not be named in any publication that may result from this study.

Please return the booklet by placing it in the enclosed envelope and mail it by **date**. I will contact you by phone within the next week to answer any questions you may have. If you have no questions and want to participate in the study, please do not hesitate to complete and mail the attached forms before my phone call. If you wish to call me with questions, my phone number is 708-216-2042, Monday through Friday, 8:00 am - 4:30 pm. I can be paged through the hospital operator after hours at 708-343-7200. If you have any questions about your rights as a research subject, you can also contact Dr. Nemchausky (Chairman of the Human Studies Subcommittee) at 708-216-2241.

Thank you in advance for your participation in this study. Although you may not directly benefit from participating in this study, I am hopeful that the results of this study will benefit future spouses of potential heart transplant patients.

Sincerely,

Eileen Collins RN, PhD (c)

APPENDIX L

UNIVERSITY OF ALABAMA CONSENT FORM

UNIVERSITY OF ALABAMA MEDICAL CENTER

BIRMINGHAM, ALABAMA

INFORMED CONSENT FORM

Patient's Name:______________________________Date:_________

Project Title: Life Quality Predictors: Heart Transplant Spouses

Patient Information

PRINCIPLES CONCERNING RESEARCH: You are being asked to take part in a research project. It is important that you read and understand these principles that apply to all individuals who agree to participate in the research project below:

1. Taking part in the research is entirely voluntary.
2. You may not personally benefit from taking part in the research but the knowledge obtained may help the health professionals caring for you better understand the disease/condition and how to treat it.
3. You may withdraw from the study at any time without anyone objecting and without penalty or loss of any benefits to which you are otherwise entitled.
4. If during your participation in the research project, new information becomes available concerning your disease or concerning better therapies which would affect your being in the research project, your doctor will discuss this new information with you and will help you make a decision about your continuing the research.

5. The purpose of the research and how it is to be done and what your part in the research will be is described below. Also described are the risks, inconveniences, discomforts, and other important information which you need to make a decision about whether or not you wish to participate. You are urged to discuss any questions you have about this research with the staff members.

AIMS OF STUDY: The purpose of this study is to assess the impact of heart transplantation on the quality of your (the spouse's) life. You have been asked to participate in this study because your spouse is currently waiting for a heart transplant. This study is also being conducted at two other medical centers. A total of 104 spouses of heart transplant candidates will be asked to participate in this study.

DESCRIPTION AND EXPLANATION OF PROCEDURE: You will be asked to complete six forms asking questions about your experience since your spouse has been waiting for a heart transplant. In addition, you will be asked about other stressors in your life, how you cope, what resources are available to you, and questions in general about the quality of your life. The entire booklet will take approximately 45 minutes to 1 hour to complete. You will then be asked to return the booklet in the stamped self-addressed envelope provided.

RISKS AND DISCOMFORTS: Risks and/or side effects related to your participation in the study are minimal. Some questions however, may make you uncomfortable. If you need assistance coping with these uncomfortable feelings, you may call the telephone number provided below and an appropriate referral will be made.

POTENTIAL BENEFITS: You may not directly benefit from participating in this study. However, future spouses of heart transplant patients may benefit from the information obtained from this study. The information will be used to educate health care professionals to the needs and experiences of spouses of heart transplant patients.

ALTERNATIVES: An alternative to participating in this study is to choose not to participate.

FINANCIAL RISKS OF PARTICIPATION: You will be paid $5 for your time and effort upon the completion of the booklet. A check will be mailed to your home. You will not incur any cost for participating in this study.

I have fully explained to ___________________________ the nature and purpose of the above-described procedure and the risks that are involved in its performance. I have answered and will answer all questions to the best of my ability.

____

(signature: Principal investigator)

INFORMED CONSENT

Project Title: Life Quality Predictors: Heart Transplant Spouses

I have been fully informed of the above-described procedure with its possible benefits and risks. I give permission for my participation in this study. I know that Connie White-Williams or her associates will be available to answer any questions I may have. I may request to speak with a member of the Medical Center Institutional Review Board. I understand that I am free to withdraw this consent and discontinue participation in this project at any time without prejudice to my medical care. I have received a copy of this informed consent document.

I agree to allow my name and medical records to be available to other authorized physicians and researchers for the purpose of evaluating the results of this study. I consent to the publication of any data which may result from these investigations for the purpose of advancing medical knowledge, providing my name or any other identifying information (initials, social security numbers, etc.) is not used in conjunction with such publication. All precautions to maintain confidentiality of the medical records will be taken. I understand, however, that the Food and Drug Administration of the United States Government is authorized to review the records relating to this project.

____
(signature: participant)

____
(signature: witness to signature)

APPENDIX M

IRB APPROVAL FORMS

Department of Veterans Affairs **REPORT OF SUBCOMMITTEE ON HUMAN STUDIES**

Project/Program Title Life Quality: Heart Transplant Spouses

Principal Investigator Eileen Collins, M.S.N.

VAMC VAH Hines, IL 60141 Review Date: 3/29/93

COMMITTEE FINDINGS:

1. The information given in the Informed Consent under the Description of Research by Investigator is complete, accurate, and understandable to a research subject or a surrogate who possesses standard reading and comprehension skills.
   ☒ YES ☐ NO

2. The informed consent is obtained by the principal investigator or a trained and supervised designate under suitable circumstances.
   ☒ YES ☐ NO

3. Every effort has been made to decrease risk to subject(s)?
   ☒ YES ☐ NO

4. The potential research benefits justify the risk to subject(s)?
   ☒ YES ☐ NO

5. If subject is incompetent and surrogate consent is obtained, have all of the following conditions been met: a) the research can't be done on competent subjects; b) there is no risk to the subject, or if risks exists the direct benefit to subject is substantially greater; c) if any incompetent subject resists, he will not have to participate; d) if there exists any question about the subject's competency, the basis for decision on competency has been fully described.
   ☐ YES ☐ NO ☒ NA

6. If the subject is paid the payment is reasonable and commensurate with the subject's contribution.
   ☒ YES ☐ NO ☐ NA

7. Comments: (Indicate if Expedited Review)

The protocol was approved with the recommendation that it be considered exempt from documentation of informed consent since it involves survey procedures for which procedures are in place to maintain the confidentiality of the subjects thereb meeting criteria for such exemption per VA Manual M-3, Part I, CHapter 9, Appendix 9C d(1). An informational letter which informs subjects of the purpose, procedures, and methods in place to maintain their confidentiality was reviewed and approved by the HSS to accompany the survey form.

RECOMMENDATION: ☒ APPROVE ☐ DISAPPROVE/REVISE

SIGNATURE OF CHAIRMAN BERNARD NEMCHAUSKY, M.D.	DATE 3-26-93

VA FORM JAN 1990 10-1223

3/18/93 IRB FULL APPROVAL NOTIFICATION

LU NUMBER: 5575

PI: Jalowiec , Anne .

TITLE: Life Quality Predictors: Heart Transplant Spouses

PI DEPARTMENT (SECTION): Nursing ( )

Thank you for your recent response to the concerns of the Board. The issues have been satisfactorily addressed. You have full IRB approval and may begin your research project.

The project is issued IRB #: 5575031893.

This approval is issued for one year. If the project is still ongoing after one year, annual review will be necessary. The dates of the annual review are listed below:

1. Annual review: 3/18/94
2. Annual review: 3/18/95
3. Annual review: 3/17/96

Forms for completion will be sent to you one month prior to the scheduled date of the annual review. You will be notified of the decision of the IRB.

You are required to maintain complete records with respect to this project. Any changes in the procotol and the informed consent document must receive prior IRB approval. Any notices or advertisements soliciting participants must also receive prior IRB approval. The IRB may audit this project at any time.

The IRB must be notified of any and all adverse events associated with this project involving a Loyola patient within 48 hours of an adverse event identification. Any notification of adverse events occurring at other investigation sites you receive is to be copied to the IRB office.

Reportable events include:

1) an event requiring discontinuation of protocol therapy;

2) an unexpected event requiring modification of protocol therapy;

3) an event requiring hospitalization;

4) an unintended event producing a prolongation of a current hospital stay;

5) an event producing injury;

3/18/93 IRB FULL APPROVAL NOTIFICATION

6) the death of a patient while receiving protocol therapy;

7) a patient enrolled on a study who is found to be ineligible; the enrollment of a patient on a study which is no longer accruing patients;

8) pregnancy occurring while on study and the study excludes pregnancy;

9) any patient who reports to you a hospital billing problem he or she is having as a result of participating in the project;

10) any unanticipated, untoward, or unexpected adverse event not covered by the above.

If the sponsor of the research project temporarily halts further patient accural the IRB is to be notified immediately along with the reason for the suspension. The study may not resume until the full board reviews and approves the corrective actions taken, if any.

The IRB is to be notified when the study permanently closes. At that time we will send you the appropriate forms to be completed.

Thank you.

Kenneth Craig Micetich

Kenneth Craig Micetich, M.D.
Chairman, Institutional Review Board for the Protection of Human Subjects,
Medical Center

UAB THE UNIVERSITY OF
ALABAMA AT BIRMINGHAM
Office of the Institutional Review Board for Human Use

FORM 4: IDENTIFICATION AND CERTIFICATION OF RESEARCH PROJECTS INVOLVING HUMAN SUBJECTS

THE INSTITUTIONAL REVIEW BOARD (IRB) MUST COMPLETE THIS FORM FOR ALL APPLICATIONS FOR RESEARCH AND TRAINING GRANTS, PROGRAM PROJECT AND CENTER GRANTS, DEMONSTRATION GRANTS, FELLOWSHIPS, TRAINEESHIPS, AWARDS, AND OTHER PROPOSALS WHICH MIGHT INVOLVE THE USE OF HUMAN RESEARCH SUBJECTS INDEPENDENT OF SOURCE OF FUNDING.

THIS FORM DOES NOT APPLY TO APPLICATIONS FOR GRANTS LIMITED TO THE SUPPORT OF CONSTRUCTION, ALTERATIONS AND RENOVATIONS, OR RESEARCH RESOURCES.

PRINCIPAL INVESTIGATOR: Connie White-Williams, RN, MSN

PROJECT TITLE: Quality of Life in Heart Transplant Spouses

____ 1. THIS IS A TRAINING GRANT. EACH RESEARCH PROJECT INVOLVING HUMAN SUBJECTS PROPOSED BY TRAINEES MUST BE REVIEWED SEPARATELY BY THE INSTITUTIONAL REVIEW BOARD (IRB).

X 2. THIS APPLICATION INCLUDES RESEARCH INVOLVING HUMAN SUBJECTS. THE IRB HAS REVIEWED AND APPROVED THIS APPLICATION ON 5-7-93 IN ACCORDANCE WITH UAB'S ASSURANCE APPROVED BY THE UNITED STATES PUBLIC HEALTH SERVICE. THE PROJECT WILL BE SUBJECT TO ANNUAL CONTINUING REVIEW AS PROVIDED IN THAT ASSURANCE.

X THIS PROJECT RECEIVED EXPEDITED REVIEW.

____ THIS PROJECT RECEIVED FULL BOARD REVIEW.

____ 3. THIS APPLICATION MAY INCLUDE RESEARCH INVOLVING HUMAN SUBJECTS. REVIEW IS PENDING BY THE IRB AS PROVIDED BY UAB'S ASSURANCE. COMPLETION OF REVIEW WILL BE CERTIFIED BY ISSUANCE OF ANOTHER FORM 4 AS SOON AS POSSIBLE.

____ 4. EXEMPTION IS APPROVED BASED ON NUMBER(S) ____.

DATE: 5-7-93

RUSSELL CUNNINGHAM, M.D.
INTERIM CHAIRMAN OF THE
INSTITUTIONAL REVIEW BOARD

The University of Alabama at Birmingham
212 Mortimer Jordan Hall • 1825 University Boulevard
Birmingham, Alabama 35294-2010 • (205) 934-3789 • FAX (205) 975-5977

APPENDIX N

TABLE 14

RANK-ORDER OF ITEM MEANS ON QUALITY OF LIFE INDEX (N=85)

Rank-Ordered Item	Mean	SD
Satisfaction		
1. Relationship with spouse	5.56	0.84
2. Children	5.49	0.75
3. Friends	5.40	0.77
4. Personal faith in God	5.36	1.10
5. Neighborhood	5.32	1.05
6. Emotional support from others	5.27	0.99
7. Home	5.24	1.05
8. Family's happiness	5.21	0.89
9. Job	5.20	1.25
11. Health care you are receiving	5.18	1.00
11. Physical independence	5.18	1.06
11. Potential to live long time	5.18	0.90
13. Standard of living	5.15	1.02
14. Ability to meet family responsibilities	5.06	1.08
15. Usefulness to others	5.05	1.08
16.5. Education	4.95	1.20
16.5. Life in general	4.95	1.12
18. Yourself in general	4.91	1.10
19. Happiness in general	4.89	1.12

Rank-Ordered Item	Mean	SD
20. Health	4.80	1.11
21. Not having a job	4.73	1.79
22. Amount of pain	4.61	1.42
23. Personal appearance	4.60	1.10
24. Achievement of personal goals	4.59	1.33
25. Control over life	4.47	1.48
26. Financial independence	4.41	1.41
27. Amount of energy for everyday activities	4.38	1.34
28. Potential for happy old age/ retirement	4.36	1.39
29. Leisure time activities	4.20	1.41
30. Peace of mind	4.11	1.58
31. Sex life	4.08	1.67
32. Family's health	3.87	1.70
33. Ability to travel on vacations	3.61	1.47
34. Amount of stress/worries in life	2.94	1.48
Importance		
1. Family's health	5.93	0.30
2. Family's happiness	5.92	0.32
3. Children	5.89	0.62
4. Relationship with spouse	5.87	0.61
5. Peace of mind	5.80	0.51
6. Health care you are receiving	5.78	0.50
7. Health	5.76	0.53
8. Ability to meet family responsibilities	5.73	0.54

Rank-Ordered Item	Mean	SD
9.5. Job	5.71	0.57
9.5. Personal faith in God	5.71	0.78
11. Amount of energy for everyday activities	5.68	0.71
12. Physical independence	5.67	0.71
13. Amount of control over life	5.60	0.83
14. Home	5.59	0.66
15. Standard of living	5.54	0.62
16.5. Financial independence	5.52	0.77
16.5. Happiness in general	5.52	0.61
18. Friends	5.51	0.61
19. Life in general	5.47	0.68
20. Potential for happy old age/ retirement	5.45	0.70
21. Usefulness to others	5.42	0.86
22. Emotional support from others	5.39	0.83
23.5. Amount of pain	5.38	0.77
23.5. Personal appearance	5.38	0.71
25. Achievement of personal goals	5.35	0.63
26. Potential to live a long time	5.34	0.68
27. Yourself in general	5.20	1.01
28. Education	5.19	0.94
29. Neighborhood	5.13	0.86
30. Leisure time activities	4.94	0.92
31. Sex life	4.80	1.10
32. Amount of stress/worries in life	4.56	1.36
33. Ability to travel on vacations	4.34	1.47

Rank-Ordered Item	Mean	SD
34. Not having a job	2.94	2.14

Note: Item scores range from 1 (very dissatisfied/very unimportant) to 6 (very satisfied/very important).

APPENDIX O

TABLE 15

RANK-ORDER OF ITEM MEANS ON SPOUSE TRANSPLANT STRESSOR SCALE (N=85)

RANK-ORDERED ITEM	MEAN	SD
1. Afraid spouse might die	2.34	0.96
2. Not knowing when transplant will take place	2.28	0.92
3. Not knowing if transplant will take place	2.19	1.02
4.5. Waiting for transplant	2.02	0.91
4.5. Not knowing if a heart will come along	2.02	0.91
6. Worrying that new heart might not work	1.84	1.10
7. Not being able to plan for future	1.65	1.08
8. Worrying about whether medical insurance will cover transplant costs	1.61	1.27
9. Worrying about paying medical bills	1.54	1.19
10. Limited finances due to spouse's illness	1.48	1.13
11. Understanding spouse's feelings while awaiting transplant	1.46	0.99
12. Worrying about paying bills in general	1.34	1.14
13. Adjusting to spouse's illness	1.28	0.91
14. Not being able to talk about fears and concerns because I have to be the strong one	1.27	1.06

RANK-ORDERED ITEM		MEAN	SD
15.	Needing to take on new responsibilities because of spouse's illness	1.22	1.06
16.	Not being able to sleep well	1.19	0.99
17.	Not having control over life	1.18	1.09
18.	Protecting spouse from everyday problems	1.14	1.00
19.	Feeling angry that more people do not donate organs	1.11	1.02
20.	Worrying about children having heart disease someday	1.05	0.97
21.	Fear of having sex because of spouse's illness	1.04	1.07
22.5.	Not being able to take vacations because of spouse's illness	0.99	0.94
22.5.	Having to make changes in lifestyle due to spouse's illness	0.99	0.91
24.	Spouse relying on me more than before	0.98	0.95
25.	Not having time for myself	0.93	1.01
26.	Needing to rely on others	0.91	0.98
27.5.	Not knowing specific facts about spouse's condition	0.85	0.92
27.5.	Others relying on me more than before	0.85	0.96
29.	Having to communicate about spouse's health problems with many different doctors and nurses	0.84	0.90
31.	Having to take time from job because of spouse's illness	0.82	0.89
31.	Less (or no) sex in life	0.82	0.95
31.	Feeling that I have no one to protect me	0.82	1.04

RANK-ORDERED ITEM		MEAN	SD
33.5.	Change in sexual activity	0.80	0.91
33.5.	Worrying that transplant might change spouse in some way	0.80	0.95
35.	Feeling that there is no hope for my spouse	0.79	1.07
36.	Lack of information about the transplant process	0.76	0.90
37.	Worrying if medical personnel will take good care of spouse while he/she is in the hospital	0.65	0.96
38.5.	Not being kept informed by the staff of spouse's condition	0.60	0.80
38.5.	Not understanding information given about spouse's condition	0.60	0.79
40.	Frequently having to take spouse to hospital/doctor's office/clinic	0.59	0.81
41.	Less (or no) affection in my life	0.56	0.81
43.	Decline in social life because of spouse's illness	0.55	0.81
43.	Not being able to do job because of spouse's illness	0.55	0.72
43.	Having to do things slower because spouse cannot keep up	0.55	0.78
46.5.	Having questions answered by medical and/or nursing staff	0.54	0.81
46.5.	Afraid to take time for self because of what others would say/think	0.54	0.78
47.	Increased conflict in my family due to my spouse's illness	0.53	0.84
48.	Close friend/family member recently died	0.51	0.98

RANK-ORDERED ITEM	MEAN	SD
49.5. Feeling that no one is concerned about my health	0.45	0.76
49.5. Having to help spouse limit fluid intake	0.45	0.70
51. Having to prepare a special diet for spouse	0.42	0.70
52. Feeling guilty about spouse getting someone else's heart	0.40	0.62
53. Having to go on or being on public assistance	0.38	0.91
54. Having to help my spouse take medications	0.36	0.69
55. Providing care for a sick or elderly relative (other than my spouse)	0.35	0.72
56. Difficulty arranging care for dependent relatives	0.29	0.72
57. Worrying about the effect of surgery on my spouse's physical appearance	0.26	0.58
58. Having to get a job because of my spouse's illness	0.25	0.75
59. Losing my job	0.24	0.68
60. My alcohol and/or drug abuse	0.09	0.33
61. My spouse's alcohol and/or drug abuse	0.07	0.34

Note: Possible range for item rating = not stressful (0)-very stressful (3)

APPENDIX P

TABLE 16

RANK-ORDER OF ITEM MEANS ON JALOWIEC COPING SCALE (N=85)

RANK-ORDERED ITEM		MEAN	SD
Coping methods used			
1.5.	Prayed or put trust in God	2.73	0.56
1.5.	Tried to think positively	2.73	0.52
3.	Tried to handle things one step at a time	2.59	0.66
4.	Thought about the good things in your life	2.55	0.68
5.	Tried to keep busy	2.49	0.89
6.5.	Tried to keep a sense of humor	2.47	0.77
6.5.	Tried to look at problem objectively and see all sides	2.47	0.80
8.	Hoped that things would get better	2.46	0.82
9.	Tried to keep life as normal as possible and not let the problem interfere	2.44	0.71
10.	Tried to keep your feelings under control	2.40	0.79
12.	Worried about problem	2.29	0.84
12.	Told self that things could be worse	2.29	0.91
12.	Tried to find out more about problem	2.29	0.87

Appendix P--Continued

RANK-ORDERED ITEM		MEAN	SD
14.	Talked problem over with family or friends	2.22	0.86
15.	Tried to keep situation under control	2.21	0.90
16.	Thought out different ways to handle situation	2.18	0.99
17.	Told self that could handle anything no matter how hard	2.19	0.91
18.	Accepted situation because little could be done	2.14	0.99
19.	Tried to see good side of situation	2.11	0.96
20.	Tried to distract self by doing something enjoyable	1.96	0.82
21.5.	Told self not to worry because everything would work out	1.93	0.95
21.5.	Practiced in mind what had to be done	1.93	0.96
23.	Tried to put problem out of mind and think of something else	1.89	0.96
24.	Kept feelings to self	1.78	1.00
25.	Tried to improve self so could handle situation	1.76	1.03
26.	Exercised or did physical activity	1.71	0.97
27.	Wanted to be alone to think things out	1.62	1.06
28.	Preferred to work things out yourself	1.61	1.15
29.	Thought about how you handled problems in the past	1.59	1.06
30.	Set up plan of action	1.58	1.12
31.	Learned something new to deal with problem	1.53	1.16

RANK-ORDERED ITEM	MEAN	SD
32. Wished that problem would go away	1.46	1.21
33. Talked problem over with someone in similar situation	1.41	1.09
34. Tried to get away from problem for awhile	1.40	0.97
35. Depended on others to help you out	1.27	0.99
37. Talked problem over with professional person	1.25	1.19
37. Waited to see what would happen	1.25	1.05
37. Compared self with others in same situation	1.25	1.09
39. Expected the worst that could happen	1.22	1.08
40. Let time take care of the problem	1.21	1.08
41. Ate or smoked more than usual	1.20	1.17
42. Used relaxation techniques	1.15	1.06
43. Got mad and let off steam	1.11	0.85
44. Daydreamed about better life	1.09	1.05
45. Tried to work out compromise	0.98	1.07
46. Took out tensions on someone else	0.93	0.77
47. Tried to change situation	0.92	1.05
48. Tried to ignore or avoid problem	0.80	1.00
49. Put off facing up to problem	0.79	1.00
50. Slept more than usual	0.72	0.92

RANK-ORDERED ITEM		MEAN	SD
51.	Resigned self to situation because things looked hopeless	0.69	0.98
52.5.	Took medications to reduce tension	0.55	0.97
52.5.	Avoided being with people	0.55	0.87
54.	Blamed self for getting into situation	0.53	0.93
55.	Told self that problem was not really important	0.48	0.84
56.	Told self that you were just having some bad luck	0.47	0.81
57.	Tried to get out of situation	0.45	0.72
58.	Did something impulsive or risky that you would not usually do	0.39	0.73
59.	Took a drink to make self feel better	0.38	0.74
60.	Told self that problem was someone else's fault	0.32	0.76
Effective coping methods			
1.	Prayed or put your trust in God	2.62	0.67
2.	Tried to think positively	2.46	0.76
3.	Tried to handle things one step at a time	2.42	0.78
4.	Thought about the good things in your life	2.39	0.87
5.	Tried to keep a sense of humor	2.24	0.85
6.	Talked the problem over with family or friends	2.22	0.89
7.	Tried to look at the problem objectively and see all sides	2.16	0.97

RANK-ORDERED ITEM	MEAN	SD
8.5. Tried to find out more about problem	2.13	0.97
8.5. Tried to keep busy	2.13	0.99
10. Tried to keep your life as normal as possible and not let the problem interfere	2.08	0.85
11. Tried to distract self by doing something enjoyable	2.01	0.93
12. Tried to see good side of situation	1.96	0.99
13.5. Thought out different ways to handle situation	1.88	1.04
13.5. Told self that things could be much worse	1.88	1.00
15. Tried to keep situation under control	1.85	0.94
16. Told self you could handle anything no matter how hard	1.81	1.04
17. Exercised or did some physical activity	1.73	1.05
18. Tried to keep feelings under control	1.72	0.98
19.5. Accepted situation because little could be done	1.69	1.05
19.5. Tried to improve self so could handle situation better	1.69	1.09
21. Practiced in mind what had to be done	1.66	0.98
22.5. Told self not to worry because everything would work out	1.56	1.05
22.5. Talked problem over with someone in similar situation	1.56	1.20
24. Hoped things would get better	1.51	1.03

RANK-ORDERED ITEM	MEAN	SD
25. Wanted to be alone to think things out	1.47	1.11
26. Learned something new to deal with problem	1.46	1.19
27. Set up plan of action	1.45	1.13
28. Talked problem over with professional person	1.41	1.33
29. Tried to get away from problem for awhile	1.36	1.07
30. Thought about how handled problems in past	1.34	1.13
31. Tried to put problem out of mind and think of something else	1.26	0.94
32. Depended on others to help you out	1.22	1.10
33. Preferred to work things out for self	1.19	1.01
34. Used relaxation techniques	1.07	1.07
35.5. Let time take care of problem	1.05	1.13
35.5. Compared self with others in similar situation	1.05	1.01
37.5. Waited to see what would happen	0.88	0.94
37.5. Tried to work out compromise	0.88	1.06
39. Kept feelings to self	0.80	0.99
40. Worried about problem	0.75	0.94
41. Got mad and let off steam	0.74	0.97
42. Daydreamed about better life	0.72	1.02
43. Tried to change situation	0.67	0.88

RANK-ORDERED ITEM	MEAN	SD
44.5. Expected the worst that could happen	0.52	0.84
44.5. Took medications to reduce tension	0.52	1.01
46. Tried to ignore or avoid problem	0.48	0.87
47. Slept more than usual	0.44	0.76
48. Resigned self to situation because things looked hopeless	0.42	0.81
49. Wished that problem would go away	0.39	0.79
50. Put off facing problem	0.38	0.76
51. Told self that problem was not that important	0.35	0.78
52. Avoided being with people	0.34	0.68
53.5. Took a drink to make self feel better	0.29	0.67
53.5. Did something impulsive or risky	0.29	0.67
55. Tried to get out of situation	0.28	0.65
56. Told self that were having some bad luck	0.26	0.64
57. Took tensions out on someone else	0.25	0.51
58. Ate or smoked more than usual	0.21	0.49
59. Blamed self for getting into situation	0.14	0.49
60. Told self that the problem was someone else's fault	0.08	0.32

Note: Possible range of scores: 0=never use/not helpful; 3=often used/very helpful

APPENDIX Q

TABLE 17

RANK-ORDER OF ITEM MEANS ON FAMILY INVENTORY OF RESOURCES FOR MANAGEMENT (N=85)

RANK-ORDERED ITEM	MEAN	SD
1. Members of family are good citizens and neighbors	2.80	0.51
2. Working members of family are respected by co-workers	2.78	0.62
3. We get great satisfaction when we can help one another in our family	2.65	0.61
4. We have enough money to cover small unexpected expenses (under $100)	2.59	0.82
5.5. It is okay for members to show positive feelings about each other	2.58	0.76
5.5. Members of family respect one another	2.58	0.62
7. Okay for family members to express sadness by crying	2.56	0.71
8.5. Members are encouraged to have own interests/abilities	2.55	0.72
8.5. We help our relatives when we can	2.55	0.61
10. We keep in touch with our relatives	2.52	0.73
11. When we face a problem, we look at the good and bad of each possible solution	2.51	0.61
12. It is important to save for the future	2.42	0.78

RANK-ORDERED ITEM	MEAN	SD
13. We understand what help we can expect from one another	2.40	0.75
14. Friends enjoy coming to our house	2.38	0.86
15. We are able to go out to eat without hurting our budget	2.36	0.87
16.5. No matter what happens, we look at the bright side	2.32	0.74
16.5. Relatives listen to our problems	2.32	0.82
18. No one could be happier than our family	2.31	0.76
19. We own a home	2.29	1.14
20. Our relatives make us feel appreciated	2.28	0.80
21. We are happier than many families we know	2.26	0.86
22. Family is as well-adjusted as any family	2.02	0.96
23. Family plans work	2.00	0.79
24. Family members understand each other	1.94	0.88
25. We would have no problem getting a loan if we wanted one	1.96	1.26
26.5. We discuss decisions with family before carrying out	1.91	0.95
26.5. We save extra spending money for special things	1.91	0.92
28. We have no problem paying bills	1.85	1.16
29. If main breadwinner lost job, could find another one	1.84	1.16
30. Family is under a lot of emotional stress	1.81	0.87

RANK-ORDERED ITEM	MEAN	SD
31. We are able to make financial contributions to good causes	1.75	1.03
32.5. Income-earning members have good benefits	1.73	1.27
32.5. We have money to cover immediate expenses	1.73	1.04
34. We have good retirement income	1.45	1.11
35. We are financially better off now than 5 years ago	1.44	1.21
36.5. Things we need to do, do not get done	1.40	0.83
36.5. Our family is a perfect success	1.40	0.94
38. We need more life insurance than we have	1.36	1.22
39. It is upsetting when things don't work out as planned	1.34	0.66
40. We worry about how we would cover a large unexpected bill	1.29	1.08
41. We feel we don't have control over direction of lives	1.28	0.93
42. Being physically tired is a problem in our family	1.20	0.84
43. Having only one person earning money is a problem	1.15	1.14
44. At times, members do things that make other members unhappy	1.14	0.74
45. We have little influence over things that happen to us	1.08	0.80
46. Many things interfere with members sharing concerns	0.99	0.91

RANK-ORDERED ITEM	MEAN	SD
47. Most money decisions are made by one member	0.96	1.06
48. We could help out a relative with financial problems	0.94	0.94
49. Members take each other for granted	0.88	0.86
50. One or more working members are unemployed	0.79	1.22
51. Some members of family have many responsibilities while others don't have enough	0.75	0.86
52. Being sad or down is a problem	0.74	0.73
53. We depend on social security retirement income	0.73	1.16
54. Certain members of family do all giving while others do all taking	0.72	0.89
55. We don't spend enough time together as a family	0.69	0.85
56. We put off making decisions	0.68	0.68
57.5. We do not plan too far ahead as many things turn out to be a matter of luck	0.66	0.78
57.5. If our family has faults, we are not aware of them	0.66	0.85
59. We have money coming in from investments	0.64	1.00
60.5. We nag each other to get things done	0.62	0.69
60.5. We have same problems over and over	0.62	0.81
62. It is hard to get members to cooperate with each other	0.60	0.73

RANK-ORDERED ITEM	MEAN	SD
63. We own land/property besides our place of residence	0.51	1.12
64. There are times we do not feel a great deal of love and affection for each other	0.44	0.74
65. We have more illnesses than others	0.41	0.68
66. Our relatives take from us but give little in return	0.39	0.74
67. We have written checks knowing there wasn't enough money to cover them	0.35	0.75
68. We depend almost entirely on welfare	0.13	0.53
69. We depend almost entirely on alimony and/or child support	0.02	0.22

Note: Scores range from 0 (does not at all describe our family) to 3 (describes our family very well).

APPENDIX R

TABLE 18

CORRELATIONS WITH QUALITY OF LIFE SCORES (N=85)

Variable	QOL Rating	QLI Score	QOLCS
Overall stress rating	-.402 p=.000	-.405 p=.002	-.460 p=.000
Subject's health rating	.345 p=.001	.490 p=.000	.476 p=.000
Coping ability rating	.532 p=.000	.387 p=.002	.524 p=.000
Impact of transplant on spouse's life	.266 p=.022	.272 p=.012	.280 p=.009
Patient's health status	.290 p=.007	.066 NS	.203 NS
Length of wait	.017 NS	-.082 NS	-.037 NS
Income	.097 NS	.111 NS	.117 NS
Age	-.048 NS	.195 NS	.084 NS
Total FIRM score	.552 p=.000	.651 p=.000	.685 p=.000
Esteem & Communication (FIRM)	.431 p=.000	.446 p=.000	.500 p=.000
Mastery & Health (FIRM)	.380 p=.000	.644 p=.000	.583 p=.000
Extended Family Social Support (FIRM)	.356 p=.000	.371 p=.000	.414 p=.000
Financial Well-being (FIRM)	.353 p=.000	.263 p=.015	.351 p=.001
Adjusted Coping Style Effectiveness (JCS)	.364 p=.001	.430 p=.000	.453 p=.000

Variable	QOL Rating	QLI Score	QOLCS
Evasive Coping Use (JCS)	-.262 p=.016	-.480 p=.000	-.423 p=.000
Fatalistic Coping Use (JCS)	-.289 p=.010	-.436 p=.000	-.407 p=.002
Emotive Coping Use (JCS)	-.366 p=.001	-.492 p=.000	-.488 p=.000
Palliative Coping Use (JCS)	-.227 p=.036	-.241 p=.026	-.267 p=.014
Positive Coping Use (JCS)	-.012 NS	-.013 NS	-.014 NS
Negative Coping Use (JCS)	-.354 p=.001	-.573 p=.000	-.528 p=.000
Adjusted Confrontive Effectiveness (JCS)	.280 p=.009	.360 p=.001	.364 p=.001
Adjusted Evasive Effectiveness (JCS)	.265 p=.015	.158 NS	.241 p=.027
Adjusted Optimistic Effectiveness (JCS)	.277 p=.010	.331 p=.002	.347 p=.001
Adjusted Palliative Effectiveness (JCS)	.257 p=.018	.332 p=.002	.337 p=.002
Adjusted Supportant Effectiveness (JCS)	.280 p=.009	.361 p=.001	.365 p=.001
Adjusted Self-reliant Effectiveness (JCS)	.248 p=.022	.355 p=.001	.343 p=.001
Negative Coping Style UXE (JCS)	.064 NS	-.173 NS	-.063 NS
Positive Coping Style UXE (JCS)	.174 NS	.226 p=.039	.229 p=.036
Total Stressor Score (STSS)	-.407 p=.000	-.464 p=.000	-.496 p=.000
Transplant Stressors (STSS)	-.345 p=.001	-.359 p=.001	-.401 p=.001
Socioeconomic Stressors (STSS)	-.290 p=.007	-.376 p=.000	-.380 p=.000
Responsibility Stressors (STSS)	-.354 p=.001	-.328 p=.002	-.389 p=.000

Variable	QOL Rating	QLI Score	QOLCS
Stressors Related to Self (STSS)	-.373 p=.000	-.456 p=.000	-.472 p=.000

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4-5-94
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