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**Coping and adjustment in persons with rheumatoid arthritis  
and cardiac transplantation**

**Perry-Simmons, Marla Jean, Ph.D.**

**The University of Arizona, 1991**

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Ann Arbor, MI 48106



COPING AND ADJUSTMENT IN PERSONS WITH  
RHEUMATOID ARTHRITIS AND  
CARDIAC TRANSPLANTATION

by

Marla Perry-Simmons

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A Dissertation Submitted to the Faculty of the  
DIVISION OF SPECIAL EDUCATION AND REHABILITATION

In Partial fulfillment of the Requirements  
For the Degree of

DOCTOR OF PHILOSOPHY

WITH A MAJOR IN REHABILITATION

In the Graduate College

THE UNIVERSITY OF ARIZONA

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THE UNIVERSITY OF ARIZONA  
GRADUATE COLLEGE

As members of the Final Examination Committee, we certify that we have read  
the dissertation prepared by Marla J. Perry-Simmons  
entitled Coping and Adjustment in Persons with Rheumatoid Arthritis and  
Cardiac Transplantation.

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Final approval and acceptance of this dissertation is contingent upon the  
candidate's submission of the final copy of the dissertation to the Graduate  
College.

I hereby certify that I have read this dissertation prepared under my  
direction and recommend that it be accepted as fulfilling the dissertation  
requirement.

James Organist  
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Date 5/2/91

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SIGNED: Marla Perry-Simmons

**DEDICATION**

To Charles Simmons, my husband, my sons Damon and Geric Poore and Jeremy Simmons, and to Ruth Perry and Krista Neis for their love and support.



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### ABSTRACT

This study examined the relationship between ways of coping and psychosocial adjustment to illness in cardiac transplant recipients and patients with chronic rheumatoid arthritis. The research questions were:

1. What coping patterns and levels of adjustment to illness are identified by heart transplant patients and rheumatoid arthritis patients?
2. What are the relationships between ways of coping and psychosocial adjustment to illness within these two populations independently and as a total chronic illness group?
3. How are cardiac transplant recipients similar to and different from patients with chronic rheumatoid arthritis regarding coping behavior and adjustment to illness?
4. Do specific coping styles seem to be linked to adjustment in certain life domains?

Participants included 64 adults with rheumatoid arthritis and 66 adults who were cardiac transplant recipients. The subjects each completed two questionnaires, the Psychosocial Adjustment to Illness



Scale and the Ways of Coping scale. They also answered four questions generated by the researcher which attempted to quantify frequency of symptoms and related degree of stress and perceived control over daily symptoms and long-term course of illness.

This study provided some evidence that people use the same coping strategies regardless of medical diagnosis. The data also suggested that coping through distancing and escape-avoidance may result in relationship problems and possibly increased psychological and work-related problems.

Further research should be conducted to examine how coping mechanisms are learned and how one's coping repertoire can be expanded to include more useful strategies.

## CHAPTER 1

### INTRODUCTION

This chapter will introduce the research problem, questions, hypotheses, and significance of the study. Conceptual background for this study will be included as well as the limitations of this study. Definitions of terms will also be included.

#### Background of Problem

Coping with chronic illness presents ongoing challenges for individuals as they survive the initial acute health threat and enter an extended period of living with an altered physiology. Overall lengthening of lifespan, improved control of infectious disease, and an increasingly aged population contribute to a growing prevalence of chronic illness in the United States (Craig & Edwards, 1983).

The diagnosis of a chronic illness changes an individual's view of self. Prior aspirations may need to be modified and roles adjusted (Pereira, 1984). Symptoms often interfere with normal activities, the medical

treatment may be limited in its effectiveness, and the treatment itself may contribute to lifestyle disruption.

#### Statement of Problem

This study was designed to examine ways people cope with the stress of chronic illness and how coping strategies relate to levels of adjustment in two populations with chronic illness.

Through examination of the coping process relative to illness, an understanding of how one adapts positively to health changes may be gained. With improved understanding of healthy coping with chronic illness should come improved skills in assisting persons toward optimal function within the reality of their physical limitations.

#### Conceptual Framework

The conceptual framework for this study was based on social-psychology theories and included the concepts of stress, coping and psychosocial adjustment.

#### The Concept of Stress

The most conventional way of conceptualizing stressors has been as discrete events which require adjustments of a behavioral, cognitive or emotional nature (Holmes & Rahe, 1967). There has been considerable debate about what aspects of life events are stressful. Proposed relevant

dimensions include the desirability or undesirability of an event, the degree to which an event was unexpected or controllable, and the amount of change required (Mueller, Edwards, & Yarvis, 1977; McFarlane, Norman, Streiner, & Roy, 1983; Wyler, Masuda, & Holmes, 1971).

Besides considering individual events as stressful there is an understanding that difficult life conditions such as chronic illness, poverty, role strains and interpersonal problems create ongoing stress (Pearlin, Lieberman, Menaghan, & Mullan, 1981; Wheaton, 1983).

Psychological stress is "a particular relationship between the persons and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well being" (Lazarus & Folkman, 1984, p. 19). What causes psychological stress in different persons can be considered through understanding of two critical processes that mediate the person-environment relationship: cognitive appraisal and coping. The evaluation that a particular person-environment relationship is stressful depends on cognitive appraisal (Coyne & Lazarus, 1980).

Cognitive appraisal is an evaluative process of categorizing an encounter with respect to its significance for well being. Primary appraisal refers to whether one is

in trouble or being benefitted. Secondary appraisal assesses what, if anything, can be done about it (Holroyd & Lazarus, 1982).

Three kinds of primary appraisal are distinguished: (1) irrelevant, (2) benign-positive, and (3) stressful. An irrelevant encounter carries no implication for a person's well being. Benign-positive appraisals occur if the outcome of an encounter is seen as positive. Stress appraisals include harm/loss, threat and challenge (Lazarus & Folkman, 1984).

In harm/loss, some damage to the person has already occurred. Threat involves harms or losses that are anticipated but have not yet happened. Threat permits anticipatory coping. Threat centers on potential harms and is characterized by negative emotions such as fear, anxiety, and anger. Challenge appraisals focus on potential for growth possible in the encounter and are accompanied by pleasurable emotions such as eagerness, excitement and exhilaration (Lazarus & Folkman, 1984).

Secondary appraisal involves evaluating what might and can be done to manage the situation. Secondary appraisal is a complex process in which one considers available coping options, the likely outcome of a given option and the likelihood one can apply a particular strategy (see

Figure 1). Outcome expectancy is a person's evaluation that a given behavior will produce certain results. Efficacy expectation is a person's conviction regarding being able to successfully execute the behavior necessary to produce the outcomes.

Primary appraisals of what is at stake and secondary appraisals of coping options interact in creating the degree of stress and strength of emotional reaction experienced (Holroyd & Lazarus, 1982).

Reappraisal refers to a changed appraisal on the basis of new information from the environment, and/or information from the person's own response. Reappraisal modifies one's interpretation of the situation. Primary and secondary appraisal are interdependent and probably influence each other (Lazarus, DeLongio, Folkman, & Gruen, 1985).

The concept of commitment is pertinent to the discussion of stress and appraisal. Commitments express what is important to a person and underlie the choices made to maintain valued ideas or to achieve desired goals. The greater the strength of a commitment, the more vulnerable the person is to psychological stress in the area of that commitment. The strength of commitment that results in vulnerability can also motivate a person to a course of action that can reduce threat and sustain coping efforts.

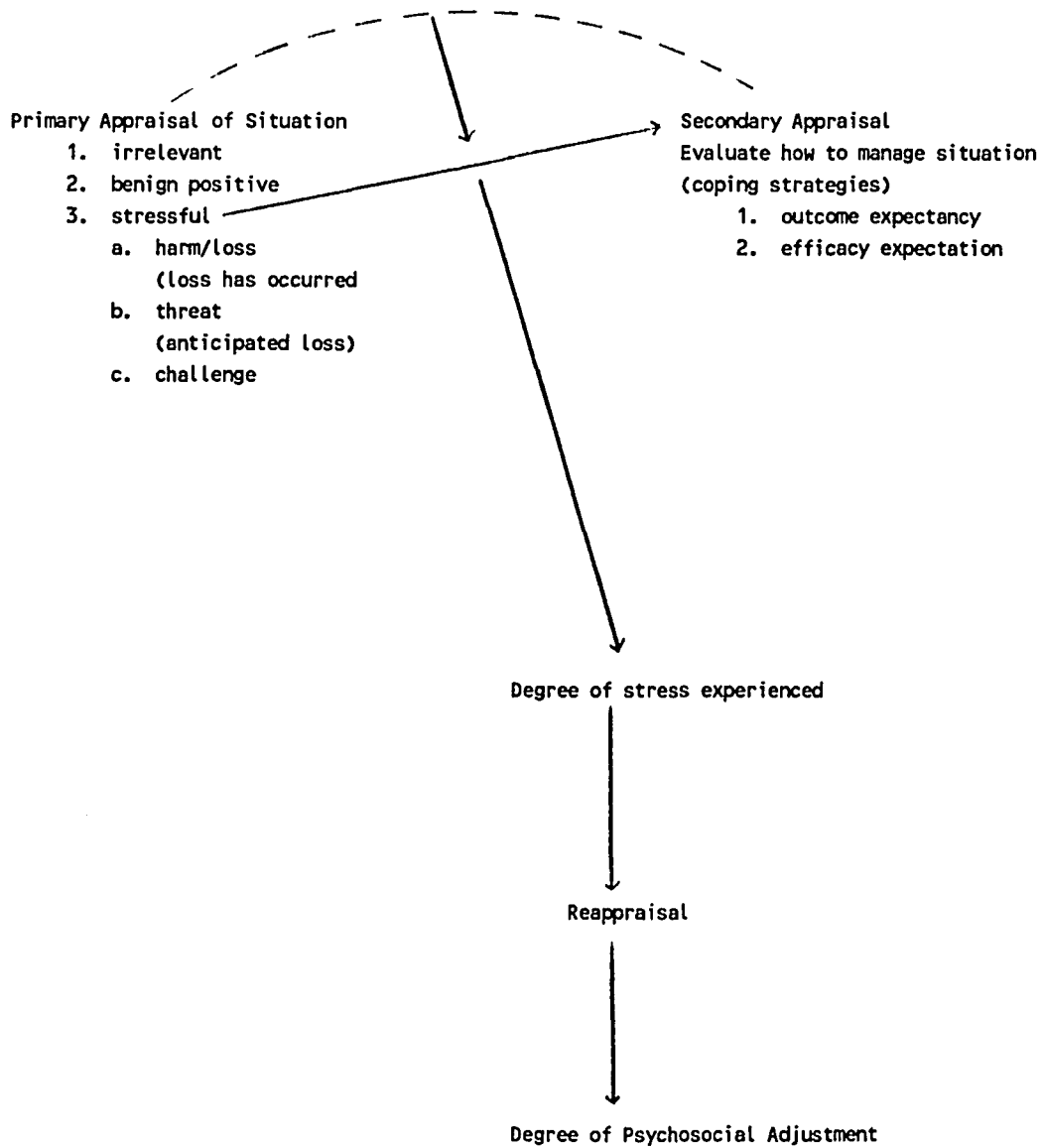


Figure 1. Conceptual model, including appraisal of situation as stressful, evaluation of coping options, and level of psychosocial adjustment reached.

Commitment determines effort. Knowing a person's pattern of commitments allows one to predict the circumstances under which a person may feel harmed, threatened or challenged (Lazarus & Folkman, 1984).

### The Concept of Coping

Coping is the word often used in describing strategies used to master, reduce, or tolerate both internal and external demands created by stressful situations (Folkman & Lazarus, 1980). In coping, one responds both to the external demands of the situation and to one's own feelings about the situation (Moos, 1976). Stone, Cohen and Adler (1979) describe coping as including problem solving efforts and the regulation of emotional distress.

Lazarus and Folkman (1984), who have researched extensively in the field of coping and stress management, offer a model containing four basic modes of coping: direct action, inhibition of action, information search, and a complex category referred to as intraphysic or cognitive coping. Lazarus and Folkman are quick to point out that any thought or act may have multiple coping functions and that all coping strategies cannot be tightly or clearly categorized.

Coping, as previously described, is defined independently of its outcome. Coping refers to efforts



made to manage demands, independent of the success of those efforts. The effectiveness of coping strategies is evident in one's level of adjustment.

### The Concept of Psychosocial Adjustment to Illness

The third component of the conceptual framework deals with psychosocial adjustment to the stress of living with a chronic illness. Adjustment refers to a positive adaptation to the realities of living with a chronic illness. It refers to maintaining a positive self-esteem, satisfying relationships, and a psychologically healthy attitude (Wright, 1980).

### Significance of the Study

Modern epidemics include coronary heart disease, hypertension, cancer, arthritis, diabetes, and more recently, AIDS. An individual's long-lived fragility make the experience of pain, of sickness, and of death integral aspects of life. Even among children and adolescents up to 18 years of age, 10% suffer from serious chronic illness of primary physical origin (Mattson, 1979). With a projected lifespan of about 75 years (Stanhope & Lancaster, 1988), most persons can expect to experience some form of chronic illness within their lives.

No one is completely prepared for the occurrence of illness or disability. With progressive decline in normal physiologic function, one confronts a downward trajectory, with plateaus and remissions and continual adjustments.

Some of the adaptive tasks inherent in having a chronic illness are: managing difficult environmental conditions and enhancing the prospects of recovery; tolerating or adjusting to negative events and realities; maintaining a positive self-image; maintaining an emotional equilibrium; and continuing satisfying relationships with others (Stone, Cohen, & Adler, 1979). Through the evolution of the coping process, individuals create strategies for meeting these tasks. Over time, changed circumstances and new feelings become integrated into a person's life and self-image.

As increasing numbers of people benefit from modern medicines and technology and survive with illnesses that in the past were terminal, there is a growing percentage of the population who are living with chronic illness. Adjustment is needed because there is often little possibility of complete return to the pre-morbid state. Periods of depression and anxiety are regularly encountered among the chronically ill (Feldman, 1974).

Through research on coping strategies and how these strategies facilitate psychosocial adjustment can come deeper understanding of how some maintain positive quality of life despite physical limitations and uncertainty about the future. As variables are identified and models of coping and adjustment elucidated, clinicians have a theoretical basis for practice in working with chronically ill clients. This research aims to contribute to the body of knowledge on illness adjustment by looking at two different chronic illnesses and analyzing data on coping behaviors and adjustment across life domains.

#### Research Questions

The research questions and related hypotheses were

1. What coping patterns and levels of adjustment to illness are identified by heart transplant patients and rheumatoid arthritis patients?
2. How are cardiac transplant recipients similar to and different from patients with chronic rheumatoid arthritis regarding coping behavior and adjustment to illness?

#### Hypotheses:

- a. There will be no difference between disease groups in the number of coping styles used.

- b. Heart transplant recipients will use more avoidant coping styles than will the rheumatoid arthritis patients.
  - c. Transplant recipients will report less control over both their day-to-day symptoms/ medication side effects and their long-term physical health than will persons with arthritis.
3. What are the relationships between ways of coping and psychosocial adjustment to illness within these two groups independently and as a total chronic illness group?

**Hypotheses:**

- a. Among the patients with rheumatoid arthritis, the positive correlation between active coping strategies and psychosocial adjustment will be greater than the positive correlation between avoidant coping styles and psychosocial adjustment. Among heart transplant recipients, the positive correlation between avoidant coping strategies and psychosocial adjustment is predicted to be greater than the positive

correlation between active coping and psychosocial adjustment.

- b. Frequency of symptoms/medication side effects and amount of related stress will predict degree of psychosocial adjustment to illness to a greater extent than disease category will.
4. Do specific coping styles seem to be linked to adjustment in certain life domains?

#### Hypotheses:

- a. Persons with chronic illness who use coping strategies including problem-focused coping, seeking social support, and positive reappraisal will have higher levels of psychosocial adjustment to illness than persons who rely heavily on the coping strategies of escape-avoidance and distancing.

#### Limitations of Study

One of the limitations of this study was that the two illness groups did not represent matched samples. Some of the study results may be attributable to demographic differences. Gender was a primary difference between the two groups with the transplant group having 84.8% males and

the arthritis group 76.2% females. This study does not address the issue of whether gender specific coping styles are common or whether men versus women typically score differently relative to adjustment levels in particular life domains. It is possible that the results of this study were less a reflection of illness type and more a reflection of gender differences.

Time since diagnosis of chronic illness also varies substantially between the cardiac and arthritic groups. Transplant recipients had been diagnosed with cardiac illness an average of 9.1 years ago, and the arthritis group was diagnosed an average of 14.2 years ago. It is possible that coping styles and adjustment domains vary over time and that the results may have been different with a more evenly matched sample.

Age was another noticeable difference. The arthritis group averaged ten years older than the transplant group.

Though not a large gap, marital status also differed between groups with 77% of the transplant recipients versus 66% of the arthritics being married. One of the nurses who worked with the transplant recipients also pointed out a potential bias in amount of available family support for the transplant recipients. She said that the typical transplant recipient relocates to Tucson and has an

extensive pre-surgery work up. She suggested that only persons with relatively intact support systems receive cardiac transplants. This may create a bias in favor of transplant recipients in the adjustment domain dealing with family relationships.

Sample selection represents an additional limitation. Respondents were not randomly selected but rather represent a group who voluntarily completed and returned questionnaires that had been mailed. Response rates differed significantly with 41% of transplant recipients and 20.4% of persons with arthritis responding. The scores on the adjustment domain Health Care Orientation may have been quite different in a random sample. These questions ask about satisfaction with health care. It is possible that only persons who had some positive feelings regarding health care providers would have completed questionnaires sent out with a cover letter from their physician.

Another limitation of the study was the use of four untested items in the collection of data on symptom frequency and associated stress and perceived control over daily symptoms and long-term health status. In an effort to encourage participation by not overburdening respondents, the researcher chose to use four simple items rather than introducing additional tested research scales.

However, this meant the use of untested items, which have only face validity and no known reliability.

Another limitation of the study was a potential bias between the two groups relative to employment data. Because of the cost of ongoing treatment and medication incurred by transplant recipients, many choose to go on Social Security Disability, which makes them eligible for Medicare. It is possible that if health care insurance were restructured that increased numbers of transplant recipients would be employed.

A limitation to doing research in the area of coping is the lack of agreed-upon meaning for frequently used terms. In reviewing the literature, there did not seem to be tight agreement as to the meaning of concepts such as social support, confrontive coping, avoidance coping, and approach coping. Comparing research results would be cleaner if there were clearly defined and shared terminology.

A further limitation of this study relates to the idea of a perceived self-concept. Much of the research on stress and coping (Lazarus & Folkman, 1984; Korner, 1970; Feldman, 1974) as it pertains to chronic illness addresses the issue of a threatened self-concept. Stress occurs when one's identity or self-concept is threatened by aspects of



one's illness. Different psychosocial domains may have varying significance to self-concepts of the respondents. However, in this study no data were collected to see which adjustment domains were tied to individual's sense of self-concept.

#### Definitions of Terms

Chronic illness is "a disease entity characterized by a slow progressive decline in normal physiological function. The disease is permanent, leaves residual disability, and is caused by irreversible pathology" (Craig & Edwards, 1983, p. 397).

Psychological stress is "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well being" (Lazarus & Folkman, 1984, p. 19).

Coping with health problems is "a process involving all the cognitive and motor activities a sick person uses to preserve bodily and psychic integrity to recover reversible impaired function and to compensate to the limit for any irreversible loss" (Miller, 1983, p. 16).

Psychosocial adjustment to illness is coming to terms with the reality of chronic illness as a state of being, discarding false

hope and destructive hopelessness and restructuring the environment in which one now functions. Adjustment implies the reorganization and acceptance of self so that there is a meaning and purpose to living that transcends the limitations imposed by the illness (Korner, 1970, p. 399).

#### Summary

This chapter has included an introduction to the research topic and the specific questions the study will answer. Hypotheses have been presented. Relationships among relevant concepts have been proposed. Limitations of this study were also reviewed.

## CHAPTER 2

### REVIEW OF LITERATURE

#### Introductory Statement

This chapter will review the literature pertinent to this study. First, there will be a review of studies related to chronic illness, successful coping with illness, psychosocial adjustment to chronic illness, and medical and psychological aspects of both rheumatoid arthritis and cardiac transplantation.

#### Studies Related to Chronic Illness

Chronic illnesses are characterized by progressive decline in function, are permanent and often only partially stabilized by medical treatment. Lewis (1983) outlines losses commonly experienced in chronic illness. They include loss of: independence, a sense of control over one's life, privacy, modesty, body image, relationships, roles, social status, possessions, financial security, means of productivity and self-fulfillment, plans for the future, and sexual functioning. Pereira (1984) describes a never ending dependency and constant learning of new limitations. Pereira (1984) emphasizes loss of control, of

plans, and of goals. "An entire identity that one valued and predicated one's self-image upon may cease to have meaning" (p. 20). Increased awareness of mortality often accompanies the diagnosis of a chronic illness. Self-esteem and self-worth may be affected as there is no immediate end to the losses incurred in chronic illness (Lewis, 1983). When illness is perceived as a loss, grief and anxiety often result (Miller, 1985). When one's self-worth is tied to physical function, appearance and expectations (both social and vocational) grief is a common outcome to a loss of physical abilities (Stewart, 1985).

Some authors suggest individual variability in response to illness. Feldman (1974) suggests that the response to illness is related to the degree it prevents one from behaving congruently with a held self-concept. He describes an existential decision faced by patients, to remain sick with no realistic hope of cure or to discover new meaning and accept the differences illness brings while maintaining dignity and worth.

The multiple and ongoing losses inherent in a chronic illness challenge a person's self-concept and the individual is faced with choices about how to reconstruct a meaningful life. Sources of stress include changes in physical ability and appearance, altered family and social

roles and changes in employment status and financial pressures.

#### Studies Related to Coping

Several authors (Dimsdale, 1976; Forsyth, Delaney, & Gresham, 1984; Noble & Hamilton, 1983; Robbins & Tanck, 1978; Moos, 1976, 1986; Weisman & Sobel, 1979; White, 1976) have done studies in the area of coping and have identified coping strategies. These 11 authors have generated lists ranging from 4 to 14 strategies and though there is overlap among the authors, a total of 33 ways to cope are identified (See Table 1). Generally, all the coping methods can be lumped under two headings: (1) problem-solving efforts, ways to deal with the threat itself, and (2) regulation of emotion (Stone, Cohen, & Adler, 1979). The coping strategies cited most frequently are social support (Dimsdale, 1976; Moos, 1976; Moos, 1986; Sidle, Moos, Adams, & Cody, 1969; Stone & Neale, 1984), exploration of reality issues and search for information (Dell Orto, 1984; Moos, 1976, 1986; Sidle, Moos, Adams, & Cody, 1969), and taking some direct action (Moos, 1976, 1986; Sidle, Moos, Adams, & Cody, 1969; Stone & Neale, 1984).

Social support provides emotional intimacy and a sense of being cared about. Ventilation of strong feelings often

Table 1. Coping strategies.

Coping	Authors
<u>Active Coping</u>	
Obtain knowledge and skill for continued self-care.	Moos (1986) Robbins & Tanck (1978) Weisman & Sobel (1979)
Actively invoking help from others.	Dimsdale (1976) Noble & Hamilton (1983)
Breaking problems into pieces - take 1 step at a time.	Moos (1976, 1986) Siddle, Moos, Adams, & Cody (1969)
Modify daily routine - adjust lifestyle. Selection and continuation of valued activities.	Moos (1976) Forsyth, Delaney, & Gresham (1984)
Participate in decision making regarding own care.	Forsyth, Delaney, & Gresham (1984)
Comply with prescribed treatment regimen.	Noble & Hamilton (1983) Robbins & Tanck (1978)
Become involved with activities. Keep mind off problems.	White (1976)
Make alternate plans for handling situations.	White (1976)
Exercise	White (1976)
Deal with role changes. Adjust to altered social relationships.	Moos (1976)
Handle physical discomfort.	Moos (1976)
Inhibition of action. Refrain from impulse.	Weisman & Sobel (1979)

Table 1, continued

Coping	Authors
Draw upon prior experience.	White (1976)
Modify the environment.	Moos (1976)
<u>Cognitive Coping</u>	
Comparative optimizing. Describe own situation relative to other patients with greater afflictions. Differential focus on the good.	Moos (1986) Forsyth, Delaney, & Gresham (1984) Dimsdale (1976)
Strategic redefinitions. Reordering life values and views on productivity, accomplishments.	Moos (1986)
Minimize struggles and adjustments caused by illness.	Forsyth, Delaney, & Gresham (1984)
Look for humorous aspects of the situation.	White (1976)
Maintain positive self-concept. Deal with social stigma of illness/disability.	Moos (1976, 1986)
Restructure view of situation to find something positive.	Moos (1986) Weisman & Worden (1976-77)
Will to live. Survival for some purpose.	Dimsdale (1976)
Adopt a belief that things will probably work out fine.	White (1976)
Set realistic goals.	Moos (1976)

Table 1, continued

Coping	Authors
Redefine normalcy. Redefine normal assimilating changes in abilities.	Forsyth, Delaney, & Gresham (1984)
Escapist fantasy - wishful thinking.	Moos (1976)
<u>Emotional Coping</u>	
Grieve losses concomitant with chronic illness. Confront inevitability of death.	Dell Orto (1984) Moos (1976)
Maintain hope despite uncertainty or downward course of health.	Moos (1976) Forsyth, Delaney, & Gresham (1984) Miller (1983)
Freely expressing both positive and negative feelings	Moos (1976, 1986) Noble & Hamilton (1983)
Active mastery of feelings when possible and acceptance of inevitability when not.	(Robbins & Tanck (1978)
Maintain feeling in control.	Moos (1976)
Rely on faith or spiritual dimensions	Moos (1976)
Be prepared to expect the worst.	White (1976)
Isolation of negative affect.	Dimsdale (1976).



occurs within the context of supportive relationships. Friends and family can assist in review of information that can lead to wise decisions. In Pearlin and Schooler's (1978) study of 2300 people, strategies through which individuals "remained committed to and engaged with relevant others" were most successful in reducing emotional distress. In a study of 132 university students (Robbins & Tanck, 1978), the factor that loaded strongest for decreasing tension in daily living was "seeking social support." In writing about coping with medical treatment, Noble and Hamilton (1983) cite social support related needs; the need to maintain satisfactory relationships, the need to express rage and hurt and the need to have attention. Schulz and Decker (1985) interviewed 100 spinal-cord-injured persons 20 years after the disability occurred. They found that persons with high levels of social support and who are satisfied with their social contacts report high levels of well being.

Cohen and Wills (1985) cite more than a hundred studies on social support. In summarizing these studies they state that the emotional support of one confiding relationship was found to be a more important predictor of health outcomes during traumatic life changes than other types of support.

Information seeking is described as one of the most universal forms of coping. In a study of 151 chronically ill adults, Felton and Revenson (1984) found that information seeking made a significant contribution to positive affect. Information seeking was characterized by an "active, instrumental orientation to illness" (p. 892). Moos (1986) writes about the need to confront reality. He describes the benefit of seeking information and considering alternative sources of action. He concludes that having information can restore a sense of control. Counte, Bieliausha and Pavlou (1983) studied 97 outpatients with multiple sclerosis and found that positive coping scores were linked with increased knowledge about the disorder.

Taking direct action to deal with the problem is Robbins and Tanck's (1978) fourth strategy in their factor analysis on coping strategies. Felton and Revenson (1984) found that confrontive approaches for dealing with illness were correlated with more positive adjustment. Moos (1986) writes about the benefit of problem-solving action. He describes a planning process in which priorities are established and roles negotiated. He suggests that participation in problem-solving contributes to a sense of competence.

### Studies Related to Successful Coping Outcomes

The successful coping outcome is seen as: coming to terms with the reality of the chronic illness, discarding both false hope and destructive hopelessness, and restructuring an environment in which one can function. It involves the reorganization of self-concept and acceptance of self. One finds a purpose of living that transcends the limitations imposed by illness (Korner, 1979, p. 399).

Weisman and Worden (1976-77) found that successful copers use confrontation (face facts), redefinition (find something favorable), and compliance with authority (confidently comply with doctor's recommendations). In contrast, poor copers used suppression and passivity. They refused to acknowledge more than a minimum about their illness and had little interaction with others.

Miller (1983) expands on the description of good copers. She found that they redefined problems into solvable forms, considered alternatives, maintained open communication, sought and accepted help, maintained hope and high morale.

Feldman (1974) expands on the importance of hope. When persons feel hopeless they accept the feared or threatening

outcome as inevitable. Hope allows one to bypass an unpleasant present and permits desired future gratifications to serve as immediate relief for current distress. Hope can save a chronically ill person from succumbing to apathy.

White (1976) reports that self-esteem is maintained by a sense of competence and inner assurance that one can do the things necessary for a satisfactory life. Miller (1983) states that an understanding that the potential ability for managing the care of health problems resides within the self is critical to the self-concept reconstruction following disability.

In reporting on indicators of wellness behavior in spinal cord injured persons, Frye (1986) generated a model in which the important variables are sense of control, level of self confidence, and level of inner strength. Hardiness is correlated with wellness seeking behavior. Hardy persons "involve selves in whatever they do (commitment) believe and act as if they can influence the events forming their lives (control), and consider change to be not only normal but a stimulus to development (challenge)" (p. 7). Self-confidence was seen as a function of self-efficacy and as resulting in a willingness to risk new behaviors. Hardy persons were seen as more involved with initiation and regulation of transactions with the environment. Dependency

was linked with feelings of alienation, powerlessness, and a sense of threat in the process of wellness seeking. In a study of cardiac patients, Seeman and Seeman (1983) found that perceived sense of control was associated with more vigorous management of illness.

Dimsdale (1976) reports that effective copers maintain a sense of mastery or personal competency. They express their autonomy through control of a portion of the universe, whether internal or external. At a minimum they have mastery over their own attitudes. Pearlin and Schooler (1978) also found mastery to be a component of successful coping. He describes mastery as the belief that life's chances are under one's own control, mastery is the antithesis of fatalism.

Levine and Ursin (1980) state that persons perceive having control over outcomes when they experience a causal link between actions and consequences. They suggest that the need to control one's personal environment is "an intrinsic necessity of life." Miller (1983) describes powerlessness as the perception that one's actions do not affect outcome. In elaborating on power, she describes nurturant power as the ability to care for self, directing others regarding self-care, being a decision maker regarding self-care. Nurturant power seems pertinent to a continued

sense of potency and positive adjustment in disabling illness. She found that as patients developed self-care skills and moved toward achieving mastery over care regimens, their perceived sense of control increased. Feeling in control was stress reducing. The author concludes that "the sense of control generates behaviors and attitudes that are health maintaining" (p. 159).

Thus, coping is conceptualized as a complex, dynamic process. How one copes is influenced by prior life experiences and people vary greatly in their ability to cope and strategies they might use with greater frequency or success. Coping includes both mechanisms to directly deal with the problem and strategies to contain uncomfortable or overwhelming emotions. Coping has behavioral, cognitive, and affective components.

#### Studies Related to Psychosocial Adjustment To Chronic Illness

Moos (1976) describes adjustment as an ongoing developmental process in which changed circumstances and new feelings are integrated into a person's life and self-image. A new reality faced and accepted.

Feldman (1974) suggests that response to illness is influenced by one's pre-morbid personality. She explains that one's self-concept evolves from defining self as "sick"

to defining self as "different". She describes a pragmatic acceptance of limitations and believes that response to illness is linked to the degree the illness interferes with behaving congruently with one's held self-concept. One defines a new meaning in life and is able to maintain feelings of dignity and worth.

Self-concept definition occurs which includes integrating an accurate perception of an altered physiology or body part. White (1976) emphasizes the importance of maintaining self-esteem and a positive self-concept. Self-concept includes the physical self or body image, functional self or role performance, personal or moral self, and self-worth. As one integrates the changes that often accompany chronic illness, a person grows to define self in terms of continuing strengths and abilities rather than as limitations or an illness entity.

Illness demands adjustment not only from the individual but also from the family (Dell Orto, 1984). Family members often experience intense feelings of powerlessness as they watch the changes occur in their loved ones. Often with the unpredictable course of the illness it becomes difficult for individuals or families to plan for the future (Forsyth, Delaney, & Gresham, 1984). When the ill person is exempt from normal role obligations, prolonged dependence on family

members can occur which can exhaust the coping abilities of the family unit (Craig & Edwards, 1983).

Cronkite and Moos (1984) collected longitudinal data on 267 married couples to study the interrelationships among predisposing factors, stress, moderating factors, and subsequent functioning. A Health and Daily Living form was used to collect personal, social and health-related data. Information on the quality of family resources was obtained through the Family Environment Scale. Coping strategies were assessed through questions regarding how the respondents handled recent stressful life events. Coping strategies fell into two categories, approach coping and avoidance coping. Approach coping included information seeking and cognitive strategies. Avoidance coping included such things as keeping feelings to self, eating out more and preparing for the worst.

In this study, Cronkite and Moos found that highly educated husbands and those with higher self-esteem used more approach coping. Men who were initially depressed, had more physical symptoms, consumed more alcohol and had lower self-esteems, use more avoidance coping strategies. Men and women who use more avoidance coping reported more depressive symptoms. There seemed to be a stress-buffering effect to approach coping. An exception to their general findings



occurred when the stressor was a partner's physical symptoms. The researchers found that there was a stress exacerbating effect when both partners used approach coping on the husband's depressed mood when faced with the stress of a partner's physical symptoms. They postulate that approach coping is possibly less effective when dealing with problems over which the individual has little control, such as physical symptoms.

Felton and Revenson (1984) studied 151 non-hospitalized patients faced with one of four chronic illnesses: hypertension, diabetes mellitus, rheumatoid arthritis, and systemic blood cancers. They evaluated the emotional consequences of using palliative and instrumental coping strategies. Information seeking was chosen as the instrumental strategy and wish-fulfilling fantasy as the other palliative strategy. Participants were interviewed twice, with a seven month space between interviews.

These authors found that information seeking, which they describe as a confrontive approach to illness, was linked to decreased negative affect, and that wish-fulfilling fantasy, an avoidant strategy, was linked to poor adjustment. Their findings also suggest a causal dominance between the predictive power of coping and that of adjustment. Their evidence suggests that information

seeking reduces negative affect rather than reduced negative affect prompting information seeking. Though there were slight differences between illness differences, they found uniformity of coping consequences across illnesses.

Felton, Revenson, & Hinricksen (1984) collected self-report data from 170 adults with chronic illnesses (hypertension, diabetes mellitus, rheumatoid arthritis, cancer). Their purpose was to describe coping strategies most effective in avoiding the negative psychological consequences of illness. Participants reported on activities of daily living using an eight-item list. They completed a ten-item version of the Health Locus of Control Scale. Coping was measured using a 55-item measure drawn from the "Ways of Coping" scale. Four measures were used to assess psychological adjustment. Acceptance of Illness, Sickness Impact Scale, Self-Esteem Scale, and the Positive and Negative Affect Subscale of the Bradburn Affect Balance Scale. Their findings suggest that particular diseases are not selectively linked with particular coping styles. Neither level of illness severity or any other illness distinction played a role in determining which coping behaviors were effective in promoting adjustment.

Greater positive affective states were associated with cognitive strategies, such as incorporating relevant information or on changing the nature of one's cognitions so as to interpret the idleness as an occasion for personal growth. Emotion based coping, which included wish-fulfilling fantasy, emotional expression and self-blame were related to poorer adjustment. These emotion-based coping strategies were significantly linked to lowered self-esteem.

In these studies on coping with chronic illness, there seems to be some consensus that confrontive or approach coping is linked with better adjustment and that avoidant or palliative coping is associated with negative affect. The question is raised, however, as to whether approach coping may be less effective than emotion-based coping when dealing with problems, over which the individual has little control.

Good copers take action based on confronting reality, they redefine problems into solvable forms. This may include searching for the aspects of a situation that are still controllable and exerting influence in these areas. They seek help and accept support, maintaining morale and hope.

### Medical Aspects of Rheumatoid Arthritis

Rheumatoid arthritis is a chronic systemic disease with manifestations primarily in the joints. Generalized septic symptoms or inflammatory involvement of nonarticular organs often accompanies the joint disease. In spite of extensive research, the etiology of rheumatoid arthritis is unknown. Research evidence supports the model that rheumatoid arthritis symptoms have their basis in an inflammatory response involving the immune system. Autoimmune mechanisms seem to play a role (Anderson, Bradley, Young, & McDaniel, 1985).

There is no known cause or cure, although promising research concentrates on possible infectious agents that may initiate the immunologic process. The sequence of events that occurs in the joint and leads to clinical manifestations of rheumatoid arthritis is known. An as yet unidentified agent enters the joint and injures small blood vessels within the synovium, with inflammation, thrombosis and local antibody production (Shumacher, 1975). It is theorized that the large number of antigens and antibodies form immune complexes which are then engulfed by white blood cells, resulting in the release of substances that damage the synovium and cartilage. As the disease progresses, the synovium becomes edematous and hypertrophied. Inflammatory

changes within the blood vessels are prominent. Large numbers of lymphocytes appear within the synovium and unimmunoglobulins are produced. Rheumatoid factors (anti-antibodies) are detectable in the serum of most patients with rheumatoid arthritis. During the chronic phases of the disease, damage to ligaments, tendons, articular cartilage, and bone occurs (Zuaifler, 1983).

The mode of onset and clinical course of rheumatoid arthritis varies from patient to patient. Some individuals experience only a mild illness involving a few joints and others suffer a progressive and deforming condition affecting multiple joints and causing damage to other organ systems (Harris, 1981).

Early symptoms include fatigue, malaise, and nonspecific arthralgia for several months. Specific joint symptoms often begin with morning stiffness and "gelling" of joints during the day. Approximately 15-20% of patients have an acute disease onset. The joints most frequently involved are the small joints of the hand and the wrist. Knees, ankles, small joints of feet, shoulders, and elbows are also common sites. The affected joint has soft tissue swelling, warmth, and tenderness. Destruction of the cartilage takes place and joint function becomes compromised. In prolonged disease, loss of bone

mineralization occurs. Loss of cartilage space and bony erosions occur later. In late stage disease, dislocation and fusion of joints can happen (Anderson, Bradley, Young, McDaniel, & Wise, 1985).

Systemic complications occur in less than 20% of persons with rheumatoid arthritis. These include neuropathies, cardiac disease (pericarditis, valvular disease), pulmonary disease (pleural effusion, interstitial fibrosis), vasculitis, myositis, and eye disease (scleritis) (Anderson, Bradley, Young, McDaniel, & Wise, 1985).

Approximately 1% of the general population has rheumatoid arthritis, with about 750 cases diagnosed per million persons annually (Masi & Medsger, 1979). The disease strikes people of all ages and sexes, but is most common between the ages of 20 and 50 years. Three women have the disease for every man affected by rheumatoid arthritis (Anderson, Bradley, Young, McDonald, & Wise, 1985).

Long-term studies suggest that most patients remain relatively functional after 10-15 years with the disease (Duthie, Brown, Truelove, Baragar, & Lawrie, 1964). Although rheumatoid arthritis can be a severe disabling disease, people rarely die from arthritic pathology.

However, there tends to be an increased mortality rate among rheumatoid arthritis patients from the same conditions that cause death in control populations (Prior, Symmons, Scott, Brown, & Hawkins, 1984).

#### Psychological Aspects of Rheumatoid Arthritis

Early psychological studies on persons with rheumatoid arthritis refer to a rheumatoid arthritis personality. An early descriptive study by Halliday (1941) portrays patients as self-restricted, detached, emotionally calm, and compulsive. Johnson, Shapiro, & Alexander (1947) postulate that persons with rheumatoid arthritis have repressed rebellious resentment against parental dominance. Using the Minnesota Multiphasic Personality Inventory, Moos and Soloman (1964) found a personality profile with a high degree of bodily concern, depression and somatization.

In a 1964 review of two decades of research on an arthritic personality, Moos reports that rheumatoid arthritis patients: (1) tend to repress and control feelings, (2) are shy and feel socially inadequate, (3) are compulsive and self-sacrificing. In his discussion of implications of these conclusions, Moos suggests that either there is a personality type that predates and may play a role in the disease or that the pain and disability

associated with the disease results in persons developing common traits regardless of previous characteristics.

A 1977 study by Wiener provides observations of people living with the incurable, chronic pain of arthritis. She describes repeated swings between feelings of hope and dread in persons living with the uncertainty and unpredictability of the disease manifestations. Her study results support the idea that there is no pre-arthritis personality.

Chronic and acute pain of varying intensity is considered a major consequence of rheumatoid arthritis. Functional impairment in activities of daily living is often of primary concern for patients. When the Tennessee Self-Concept Scale was used to assess self-esteem in a sample of hospitalized rheumatoid arthritis patients, low scores on body image (physical self-esteem) were reported (Spergel, Ehrlich, & Glass, 1978).

Darby and Schmidt (1988) reviewed 100 psychiatric consultations on rheumatology patients. Twenty-nine were patients with rheumatoid arthritis. Nineteen of the 29 had either dysthymic disorder (8), adjustment disorder with depressed mood (7), or a major depressive episode (4). They speculate there may be a tendency to over-diagnose a depressive disorder in patients with rheumatoid arthritis



because the somatic symptoms of depression can be the same as symptoms of the illness itself.

McFarlane and Brooks (1988) used a longitudinal design to examine the impact of rheumatoid arthritis on one's psychological state and attitudes. Using tools to assess disability, anxiety and depression, attitudes to illness and illness behavior, and successful adaptation to illness, they followed 40 patients for 3 years. They found that duration of illness had no significant relationship to levels of anxiety or depression. Similarly the number of psychological symptoms was not significantly correlated with measures of disease activity. There was an inverse relationship between depression and pain that approached significance. Irritability was significantly correlated with morning stiffness ( $r = 0.61$ ). Relative independence was found between disease severity, duration of illness and attitudes to illness. These authors conclude that "there is little evidence to support the view that the psychological profiles of patients with rheumatoid arthritis can be explained by the severity, activity or duration of their illness" (p. 930).

Hawley and Wolfe (1988) investigated the interactions between anxiety and depression, demographics and disease activity. They followed 400 patients with rheumatoid

arthritis for 4 1/2 years, assessing their status at six month intervals. Ninety-eight point seven percent of patients had scores higher than 0 on a 0-4 anxiety scale. Ninety-five point five percent had depression scores higher than 0 on a 0-4 scale. Anxiety scores were higher than depression scores and more symmetrically distributed suggesting that anxiety is common in rheumatoid arthritis patients. There was little change in psychological variables over time.

They investigated the relationship of the change in anxiety and depression to change in clinical disease variables (pain, active joints, disability index). Anxiety was correlated with disability slopes and depression slopes. The depression slope correlated with slopes of disability and active joints.

Twenty-five percent of the variance in initial anxiety and depression scores was explained by clinical and demographic variables. Therefore, most of the anxiety and depression was not explainable as secondary to their illness or demographic factors. Coping mechanisms appear to buffer the effect of disease activity on psychological scores.

Early studies suggesting arthritic personality were largely anecdotal and have not been substantiated by more stringent investigations. Negative personality

characteristics noted among arthritis patients are more feasibly explained as reactions to this chronic disease rather than as causal factors. Effective use of coping strategies may be an important factor relative to the long term psychological adjustment of arthritis patients.

Rheumatoid arthritis patients do experience significant stress and unpredictability in their lives. However, Hawley and Wolfe (1988) did not find support for an association between depression and anxiety and the clinical features of rheumatoid arthritis. McFarlane and Brooks (1988) also found the psychological state of the patient and the level of physical impairment to be independent of each other. Factors other than severity and duration of physical symptoms are mediating psychological adjustment.

#### Medical Aspects of Heart Transplantation

Transplantation of a heart into a human being began in January 1964 when a semi-comatose, 68 year old man with a recent leg amputation and a long history of hypertensive cardiovascular disease, received a chimpanzee heart in Jackson, Mississippi. The small primate heart was overwhelmed by the volume of venous blood return and he died one hour later (Griep & Ergin, 1984).

During the 1960s, canine cardiac transplantation demonstrated reliable survival times of more than one year

and a number of centers prepared for human cardiac transplantation. On December 3, 1967 in Cape Town, South Africa, the heart of a young man dying of a brain injury was transplanted into a 54-year-old man with end-stage ischemic heart disease. The recipient recovered from the surgery and lived for 18 days. In 1968, 102 cardiac transplants were performed in 17 countries (Griepp & Ergin, 1984).

The June 1986 Registry of the International Society of Heart Transplantation includes data off 2577 patients who had received heart transplants.

Eighty point six percent were men and 15.5% were women. The mean age was 39.8 plus or minus 12 years with a range of 4 days to 66 years. The number of transplants per year has increased substantially with 32 in 1976, 117 in 1981 and 962 in 1985. Ninety-six point six five percent received transplant because of either cardiomyopathy or coronary artery disease (Solis & Kaye, 1986).

Criteria commonly used to be considered as a transplant recipient are as follows: The patient has New York Heart Association Class IV cardiac disability (essentially a bed-to-chair lifestyle) and/or has an estimated life expectancy of less than six months. Other major organ systems are disease free and the patient has no infections and no recent history of pulmonary embolisms.

There must be an intact social support network and a history of good compliance with medical instructions. Patient and family must be able to understand potential benefits, risks and limitations and be able to give informed consent. The patient must be able to fund the expense of the transplant and post-transplant medical care (Christopherson, 1982). Average hospital and ancillary costs in 1980 were \$65,662 for the transplantation and post-operative in-hospital recovery.

The International Heart Transplant Registry reports a world-wide one year survival rate of 80% and a six year survival rate of 47% for recipients transplanted since 1978 (Lough, Lindsey, Shinn, & Stotts, 1987). In 1983, the USFDA approved the use of cyclosporine as an immuno-suppressive agent and it has largely replaced azathioprine usage. Most recipients (99.3%) are concomitantly maintained on oral prednisone. Medical complications that result from chronic immuno suppression in heart transplant recipients are: osteoporosis (18.2%), vision disorders (14.3%), back or spine disorders (8.8%), and cancer (6.1%). Medical complications include infection, rejection and coronary atherosclerosis (Lough, Lindsey, Shinn, & Stotts, 1987).

A study by Emery and Copeland (1985) reported causes of death in 24 heart transplant patients. Causes of death

were: acute or chronic rejection, 8; infection, 4; failure of donor, 2; renal failure, 2; arrhythmia, 1; and lymphoma, 1. Of 2577 cases reported to the International Society for Heart Transplantation, 15.47% died within the 90 days post transplant (Solis & Kaye, 1987).

Survival statistics have improved since the introduction of cyclosporine. The International Society for Heart Transplantation reports a one year survival of 87.14% for cyclosporine-treated patients and a 66% rate for patients not receiving cyclosporine. The four year survival is 76.5% and 41.9% respectively (Solis & Kaye, 1987).

The effect of age on survival was examined, looking at ages 0-60 years. No significant age to survival factor was found (Solis & Kaye, 1987).

#### Psychological Studies on Heart Transplantation

As realities regarding patient survival become more optimistic, researchers turned to consideration of psychological aspects of heart transplantation. The person who is evaluated as a candidate for transplant has typically suffered pain, fatigue and shortness of breath for years (Allender, Shisslak, Kaszniak, & Copeland, 1983). When told that transplantation is the only hope for survival, many react with fear and disbelief and may behave in angry, hostile, demanding ways (Watts, Freeman, McGiffin, Kirklin,

McVay, & Karp, 1984). They are concerned about whether they will be accepted into the program and experience feelings of helplessness and loss of control (Harvison, Jones, McBride, Taylor, Wright, & Chang, 1988).

During the waiting period, anxiety may increase as physical condition deteriorates (Allender, Shisslak, Kaszniak, & Copeland, 1983). There may be financial concerns and decreased self-esteem due to inability to fulfill work and family roles. There may be feelings of guilt knowing that someone must die before he or she can live (Harrison, Jones, McBride, Taylor, Wright, & Chang, 1988).

Immediately postsurgically is often a time of decreased stress. Improvement in cardiac output brings decreased fatigue, dyspnea and frequently a subjective improvement in cognition (Watts, Freeman, McGriffin, Kirklin, McVay, & Karp, 1984). During this period, patients deal with accepting their new heart as their own. The symbolic meaning of a heart can complicate this acceptance (Allender, Shisslak, Kaszniak, & Copeland, 1983). Isolation and restriction of visitors is stressful (Harrison, Jones, McBride, Taylor, Wright, & Chang, 1988).

Demoralization and transient depression often accompany the first rejection episode (Allender, Shisslak, Kaszniak, &

Copeland, 1983). Immunosuppressive regimens are intensified following biopsy evidence of rejection:

Steroid-induced mental changes can present as a primary disturbance of mood, mimicking a major depressive episode with impaired appetite, sleep, concentration, and depressed mood; a manic episode with decreased need for sleep, hyperactivity, euphoric mood, hypersexuality, or hyperreligiosity; an acute schizophrenic episode with hallucinations, persecutory delusions, and loose association; or an acute delirium with disorientation and confusion (Watts, Freeman, McGriffin, Kirklein, McVay, & Karp, 1984, p. 246).

As the rejection or infection resolves the depression usually lifts. Patients come to realize that rather than being well, they have traded previous cardiac symptoms for the new problems of rejection and infection (Allender et al., 1983).

Frustration and boredom can accompany hospitalization. There is anxiety, thought about leaving the security of 24-hour nursing care and the immediate availability of medical staff (Allender et al., 1983). The adjustment from the "sick" to the "well" role as a family member can be stressful. And because of the high cost of cardiac



transplantation, financial stress can be significant (Watts et al., 1984).

Questionnaires returned from 11 centers representing 595 recipients report these problems following initial hospitalization: depression/mood alterations, 72%; personality changes, 45%; impotency, 63%; chronic pain, 27%; family stress, 81%; non-compliance, 72%; (McAleer, Copeland, Fuller, & Copeland, 1985).

Lough, Lindsey, Shinn and Stotts (1987) studied 104 patients who were more than six months post-transplant and measured symptom frequency and distress as they affect quality of life. The symptoms that were more frequent with cyclospoine and corticosteroid therapy were excessive hair growth, acne, depression, mood swings, and tremors. The symptoms reported by the azathioprine and corticosteroid recipients were bruises, fragile skin and poor vision. Symptoms that were frequent in over 20% of recipients irrespective of immunosuppressive drug protocol were changed facial appearance, changed bodily appearance, pain, overeating, fatigue, lack of sleep, and decreased interest in sex. Impotence was the most upsetting symptom reported by men (48-69%). Mood swings and depression were distressful to 32% of the cyclosporine group.

In this study, 89% of heart transplant recipients report their current quality of life as good to excellent. Quality of life was negatively correlated with both symptom frequency and symptom distress. Thus, although heart transplant recipients report medical and psychological symptoms, the majority perceive the symptoms as having a relatively small impact on the quality of their lives.

A study of 75 adult heart transplant patients examined life change since transplant and impact on family life, work and social life, relationships and feelings about self.

The recipients reported considerable improvement in physical condition, with improved physical endurance. The recipients reported

positive feelings of self accomplishment, with improved future outlook and social support systems from family and friends, and an improved decision making process with a greater sense of independence. All of these concepts are linked to self-esteem and to the belief that adaptation following heart transplantation represents a major accomplishment (Lough, Lindsey, Shinn, & Stotts, 1985, p. 447).

Personal relationships were valued more highly than prior to transplant and less than 10% experienced a change

in family make-up as a result of heart transplantation. Allender, Shisslak, Kaszniak, & Copeland (1983) had found that approximately one-third of families experience significant marital and family problems--post-transplantation. However, they concluded that these problems were "exacerbations of previous difficulties that have simply become more acute due to the additional stress of the transplant patient's convalescence (p. 231).

The financial situation and physical appearance changed for the worse for almost all recipients (Lough, Lindsey, Shinn, & Stotts, 1985). Twenty-six percent reported changes for the worse in their daily lives. Ninety-five responded that they would again choose transplantation given their situation and current knowledge.

Concerns most commonly discussed in a support group for heart recipients were issues about reemployment and health care coverage (Suszycki, 1986).

An Australian study reporting on 47 patients, reveals that 89% were satisfied with family life, 74% were satisfied with their social life. Eighty-seven percent had experienced no change in marital status, however, only 50% were satisfied with their sexual life. The authors suggest that these results imply a quality of life compatible with

the normal population (Harvison, Jones, McBride, Taylor, Wright, & Chang, 1988).

#### Contrasts Between Cardiac Transplant and Rheumatoid Arthritis

There are some substantial differences between the experience of having a cardiac transplant and having rheumatoid arthritis (see Table 2). Perceived life threat is the first arena of difference. To be considered a transplant candidate, one's cardiac condition must be considered to be approaching a terminal dimension. Rheumatoid arthritis is not considered a terminal diagnosis.

Pain is another criteria on which the two health conditions vary. Arthritis is a painful disease, especially in areas of new inflammation. Pain is not a primary component of the transplant patient's experience.

The two health conditions also differ by how much it costs to provide treatment. Cyclosporine is expensive, yet mandatory for continued stability. The heart transplant itself is so costly that finances alone preclude some from accessing the surgery.

Dependence on medical care is another dimension of difference between the two conditions. With the potential for infection looming, the transplant patient's survival is dependent on follow through with medical care. Persons with

Table 2. Differences in illnesses.

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Dimension of Comparison	Cardiac Transplant	Rheumatoid Arthritis
Perceived Life Threat	+	o
Pain	o	+
Cost	+	o
Dependence on Medical Care	+	o
Magnitude of Invasiveness of Medical Procedures	+	o

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arthritis will incur greater suffering without skilled medical intervention, but their survival is not contingent on treatment.

Finally, magnitude of invasiveness of medical procedure is considered. The transplant recipient has his or her sternum sawed open, heart cut out, and another person's heart sewn in place. The person with arthritis may or may not experience surgery as part of the treatment. Even joint replacement seems of symbolically less impact than heart replacement.

#### Summary

This chapter reviewed current literature pertaining to coping with chronic illness and psychosocial adjustment to illness. Studies were reviewed that addressed medical and psychological aspects of rheumatoid arthritis and cardiac transplantation.

Three realms of coping were identified: active coping, cognitive coping, and emotional coping (Stone, Cohen, & Adler, 1979). Studies related to coping conclude that successful copers use confrontive or approach strategies in dealing with stressors (Weisman & Worden, 1976-77). Competency or a sense of control is maintained through problem-centered coping (White, 1976). Poor copers are apt to use suppression, avoidance or passivity when faced with

difficulties (Felton & Revenson, 1984). Particular diseases are not associated with particular coping styles (Felton & Revenson, 1984).

Rheumatoid arthritis is a chronic, progressive illness which commonly manifests with joint pain, fatigue and malaise (Anderson, Bradley, Young, McDaniel, & Wise, 1985). Early studies which postulated an "arthritis personality" which predisposed an individual to arthritis have not been confirmed by more recent rigorous research. An association between depression and anxiety and the clinical features of arthritis has not been supported. Level of physical impairment and psychological state appear to be independent of one another (Hawley & Wolfe, 1988).

Heart transplantation is a relatively recent, invasive and dramatic life saving procedure restricted for persons with potentially terminal cardiac disease (Christopherson, 1982). Psychological symptoms reported by transplant recipients include depression, anxiety and personality changes (McAleer, Copeland, Fuller, & Copeland, 1985). In one study 89% of heart transplant recipients reported quality of life as good to excellent (Lough, Lindsey, Shinn, & Stotts, 1987).

## CHAPTER 3 METHODOLOGY

### Introductory Statement

This chapter describes the sample selection and setting, protection of human subjects, tool selection and design, procedures, method of data collection, and data analysis for this study.

### The Sample

This study population was 66 adults who had a cardiac history of at least five years, who were between six months and six years post-heart transplant and 64 adults with at least a five year history of rheumatoid arthritis. The cardiac transplant recipients had been diagnosed with cardiac illness an average of 9.1 years. Persons with rheumatoid arthritis had been arthritic an average of 14.2 years.

Heart transplant patients were chosen because very little has been studied about their post-surgery adjustment and they have several lifestyle alterations which could demand coping. Routine medical examinations are important, medications are usually part of treatment, lifestyle



changes such as avoiding crowds may limit freedom, and they live with uncertainty regarding their long-term prognosis.

Rheumatoid arthritis patients were chosen because their chronic illness is different from the transplant's experience in meaningful ways. Dimensions in which the two illnesses vary include acute vulnerability to death, magnitude of invasiveness of medical procedures, financial cost of treatment, level of dependence on medical care, degree of ongoing pain, and size of cohort group.

Demographically, the two diagnostic groups differed extensively. Of the transplant recipients, 84.8% were male and 15.2% female. The arthritis respondents were 22.6% male and 77.4% female (Table 3). The mean age of transplant recipients was 53.3 years (standard deviation 12.9) versus 63.1 years (standard deviation 11.6) in the arthritis group. Data on marital status indicated that 77.3% of the transplant recipients and 68.9% of the arthritis patients were married (Table 4). Educational attainment was somewhat higher among the arthritis patients with 87.1% having completed two years of college versus 77.3% of the transplant recipients (Table 5). Income levels were similar though slightly higher for persons with arthritis (Table 6). Employment status differed significantly with 65.2% of transplant recipients claiming

Table 3. Sample population by gender.

	Frequency		Percent	
	R.A.	C.T.	R.A.	C.T.
Male	14	56	22.2	84.8
Female	48	10	76.2	15.2
missing data	1	0	1.6	0

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R.A. = rheumatoid arthritis patients

C.T. = cardiac transplant patients

Table 4. Sample population by marital status.

	Frequency		Percent	
	R.A.	C.T.	R.A.	C.T.
Single	3	5	4.8	7.6
Divorced	7	8	11.1	12.1
Married	42	51	66.7	77.3
Widowed	9	2	14.3	3.0
missing data	2	0	3.2	0

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R.A. = rheumatoid arthritis patients

C.T. = cardiac transplant patients

Table 5. Sample population by education level.

	Frequency		Percent	
	R.A.	C.T.	R.A.	C.T.
Grades 1-6	2	2	3.2	3.0
Grades 7-8	4	2	6.3	3.0
Grades 9-12	33	25	52.4	37.9
2 Years College	15	22	23.8	33.3
4 Years College	4	4	6.3	6.1
Graduate School	4	11	6.3	16.7
missing data	1	0	1.6	0

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R.A. = rheumatoid arthritis patients

C.T. = cardiac transplant patients

Table 6. Sample population by income level.

	Frequency		Percent	
	R.A.	C.T.	R.A.	C.T.
0-\$6,000	6	11	9.5	16.7
\$6,000-\$12,000	12	12	19.0	18.2
\$13,000-\$25,000	20	18	31.7	27.3
\$26,000-\$40,000	11	9	17.5	13.6
\$41,000-\$80,000	7	7	11.1	10.6
over \$81,000	3	7	4.8	10.6
missing data	4	2	6.3	3.0

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R.A. = rheumatoid arthritis patients

C.T. = cardiac transplant patients

disability status versus 30.2% of the arthritis group (Table 7). Some of the difference in employment status may be a function of difference in age with more arthritis persons describing themselves as retired (40.7% versus 13.6%).

The two medical diagnostic groups differed substantially with regard to frequency of illness- and medication-related symptoms/side effects. Almost constant symptoms were reported by 65.5% of persons with arthritis and by 32.8% of transplant recipients. Those reporting that they seldom had symptoms numbered 34.4% in the arthritis group and 15.5% in the cardiac transplant group. Daily symptoms were reported by 79.3% of persons with arthritis and 53.1% of the transplant recipients.

The two illness groups also varied regarding perceived level of stress associated with medication symptoms/side effects. Moderate to extreme levels of stress related to their symptoms was reported by 93% of the arthritis respondents and 54.5% of the transplant recipients. Only 1.6% of the arthritis group reported symptoms were "not at all stressful," while 27.3% of the transplant recipients described symptoms as "not at all stressful."

When asked about how much control they believed they had over daily symptoms and/or medication side effects,

Table 7. Sample population by employment status.

	Frequency		Percent	
	R.A.	C.T.	R.A.	C.T.
Employed Full-Time	10	10	15.9	15.2
Employed Part-Time	6	4	9.5	6.1
Retired	24	9	38.1	13.6
Disabled	19	43	30.2	65.2
missing data	4	0	6.3	0

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R.A. = rheumatoid arthritis patients

C.T. = cardiac transplant patients

8.2% of the arthritis respondents reported "absolutely no control" versus 19.7% of the transplant recipients with the same response. However, only 7.9% of the arthritis group reported an "extreme amount of control" compared with 21.2% of the transplant group. The arthritis respondents had a fairly bell-shaped curve in response to this question with 65% describing control over daily symptoms as between "some control" and "substantial control." The transplant recipients had a bimodal response to this item with 40.9% rating themselves as having either "absolutely no control" or an "extreme amount of control."

Regarding the amount of control participants believed they had over the long-term course of their health status, the transplant recipients reported higher levels of perceived control than did persons with arthritis. A "large" or "extreme" amount of control was reported by 13.1% of the arthritis group versus 43% of the transplant group.

#### Protection of Human Subjects

The proposed research was reviewed by the Human Subjects Committee of the University of Arizona, College of Medicine. To assure human subjects protection, all identifying information about participants was encoded. A disclaimer was provided for each participant, describing



the purpose of the study, its no-risk status, and assurance of anonymity. Withdrawal from the study would have been permitted at any time without incurring ill will.

### The Setting

The setting for this study was a large southwestern university with an active heart transplant unit and an active rheumatology department. Access to patients was arranged through the director of the heart transplant team and two rheumatology physicians. The researcher presented the study to the transplant team coordinators and the rheumatology department head for review (see Appendix A for letters from sponsoring physicians).

### Instrumentation

Folkman and Lazarus' (1988) Ways of Coping and Derogatis and Lopez's (1983) Psychosocial Adjustment to Illness scales were the instruments used. A questionnaire regarding demographic history of illness was designed by the researcher. The tools are discussed below in the order of appearance in the conceptual model.

#### Demographic/History of Illness Data Tool

A tool was designed to obtain descriptive, demographic information as well as specific illness history data (see Appendix B). Demographic variables include sex, age,

current employment status, marital status, income level, and educational level. These items were developed with input from the medical specialists.

#### Ways of Coping

The "Ways of Coping," revised, 1985 (Consulting Psychologists Press, Inc.) is a 66-item questionnaire containing a variety of thoughts and behaviors used to deal with the internal and external demands of specific stressful life events (see Appendix B). The subject is asked to recall the most stressful illness-related situation they have encountered in the past week and to use the questionnaire to document their reaction to that stressor.

Three different populations samples were used in the validity studies of this questionnaire. The community sample included 75 married couples with husbands and wives being interviewed separately by different interviewers. A student sample consisted of 108 undergraduates. The largest sample was 425 medical students.

The response format is a four-point Likert scale. Three factor analyses studies using alpha and principal factoring with oblique rotation have been done on the tool and the analyses yielded very similar factor patterns. The alpha scores on the eight scales range from .61 to .79.

The eight coping scales are: confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem solving, positive reappraisal.

### Psychosocial Adjustment to Illness Scale

The Psychosocial Adjustment to Illness Scale Self-Report (PAIS-SR) is a 46-item self-report scale (Derogatis, 1986) (see Appendix B). Psychosocial adjustment is understood as being multidimensional and associated with successful participation in normed adult roles. The PAIS-SR measures adjustment in seven psychosocial areas.

The first domain is Health Care Orientation which is concerned with the nature of the respondent's attitudes about health care, perceptions of health care providers, quality of health information, and expectancies regarding one's illness.

Vocational Environment is the second domain. The vocational domain reflects the impact that the medical disorder has on vocational adjustment.

The third domain is Domestic Environment. This domain is designed to assess problems in adaptation which are illness-induced and experienced by the family unit.

Sexual Relationships is domain number four. The Sexual Relationship domain provides information about the

quality of sexual functioning as related to the patient's illness.

Extended Family Relationship is the fifth domain. These items measure disruption in extended family relationships.

The sixth domain is Social Adjustment which reflects the patient's current leisure and social activities as well as changes in these activities subsequent to onset or progression of illness.

The final section is Psychological Distress. The Psychological Distress domain taps dysphoric thoughts and feelings associated with the patient's illness. Evaluated in this domain are: anxiety, depression, and hostility, as well as decreased self-esteem, body image problems, and inappropriate guilt.

Four illness population samples were used in the development of the PAIS. They were lung cancer patients (n = 120), renal dialysis patients (n = 272), acute burn patients (n = 231), and essential hypertension patients (n = 447).

In developing the PAIS, specific domains were identified and then, items constructed to measure that domain. The average domain intercorrelation is .28,

suggesting success in creating items which address separate domains of adjustment.

In a study with breast cancer patients the PAIS was administered at the same time as several other psychological measures (Derogatis, Abeloff, & Melis, 1979).

The Global Adjustment to Illness Scale (GAIS) had a very high total correlation score with the PAIS ( $r = 0.81$ ). Of the domain scores, Health Care Orientation is highest ( $r = 0.80$ ), Domestic Environment is next ( $r=0.76$ ), followed by Psychological Distress ( $r = 0.70$ ). These are primary aspects of overall adjustment to illness.

The Patient's Attitudes, Information and Expectancies Scale (PAIE) was used in the validation study as a simple measure of the patient's attitudes and expectancies concerning his illness, and the information processed. Overall correlation with PAIS total score was 0.64. A particularly marked correlation was found between the PAIE and the Health Care Orientation domain ( $r = 0.88$ ).

In another validity study (Derogatis, 1986), the PAIS had a total score correlation of .60 with the SCL-90-R suggesting that psychosocial adjustment involves more than the simple absence of psychological symptoms. The SCL-90-R is a measure of psychological symptomatic distress.

Kaplan-DeNour (1982) compared the PAIS-SR scores of renal dialysis patients rated as "good" and "bad" adjusters by their physicians. They found statistically significant differences between the groups on PAIS-SR total and domain scores.

#### Data Collection

Cardiac transplant and rheumatoid arthritis patients were sent packets which included an introductory letter from their physician, an explanatory statement from the researcher, the two study questionnaires, demographic questions, and brief items related to issues of control and symptom severity (Appendix B). Postage-paid envelopes were included so that willing participants could return their responses.

#### Data Analysis

Frequencies and percentages, as well as other descriptive data, were compiled using the Statistical Package for the Social Sciences (SPSS-X) computer program.

#### Statistics

Descriptive statistics were used to answer Research Question 1: What coping patterns and levels of adjustment to illness are identified by heart transplant patients and rheumatoid arthritis patients? In addition discriminant

analysis was done to see whether it was possible to predict medical diagnostic group based on coping responses or adjustment scores. Group membership was the criterion variable in the analysis. The eight coping patterns and seven adjustment domains were separately entered in a stepwise fashion to discriminate transplant from arthritis patients.

Research Question 2 was how are cardiac transplant recipients similar to and different from patients with chronic rheumatoid arthritis regarding coping behavior and adjustment to illness? T-tests were used to measure whether the two diagnostic groups differed significantly by coping styles and levels of adjustment. Two hypotheses related to this question. The first was that there would be no between-group differences in the number of coping styles used. The second hypothesis was that heart transplant recipients would use more avoidant coping styles than would the rheumatoid arthritis patients. Chi-square was used to measure both of these hypotheses.

The third research question was what are the relationships between ways of coping and psychosocial adjustment to illness within these two groups independently and as a total chronic illness group? Correlational methods were used to answer this question. Related to this

research question were the hypotheses that (1) among patients with rheumatoid arthritis, the correlation between active coping strategies and psychosocial adjustment would be greater than the correlation between avoidant coping styles and psychosocial adjustment and (2) among heart transplant recipients, the correlation between avoidant coping strategies and psychosocial adjustment would be greater than the correlation between active coping and psychosocial adjustment. An additional hypothesis related to this question was that frequency of symptoms/medication side effects and amount of related stress would predict psychosocial adjustment to illness to a greater extent than disease category. Pearson chi-square was used to test this hypothesis.

The fourth research question was do specific coping styles seem to be linked to adjustment in certain life domains? Correlational methods were first used to measure relationships between coping strategies and adjustment domains. Multiple regression analysis was used to assess which coping strategies contributed significantly to variation in adjustment to illness domains.

The hypothesis related to this question was that persons with chronic illness who use coping strategies including problem-focused coping, seeking social support



and positive reappraisal would have higher levels of psychosocial adjustment to illness than persons who relied heavily on the coping strategies of escape-avoidance and distancing. Analysis of variance was used to measure this hypothesis.

#### Summary

This chapter described the study's setting and sample selection, tool selection, and design, along with data collection method and data analysis.

CHAPTER 4  
RESULTS AND DISCUSSION

Introductory Statement

This chapter includes results and discussion of the study. The chapter begins with a report of the statistical procedures done on the questionnaires returned by the participants. Coping patterns and levels of adjustment to illness in each medical diagnostic group are discussed. Next are comments on the relationship between ways of coping and psychosocial adjustment to illness within each population independently. Fourth are discussions regarding how cardiac transplant recipients are similar to and different from persons with rheumatoid arthritis in their coping behavior and adjustment to illness. Lastly is discussion on coping styles and whether they are linked in general to adjustment in certain life domains.

Research Question 1

The first question asks what coping patterns and levels of adjustment to illness are identified by heart transplant recipients and rheumatoid arthritis patients.

In descending order of frequency, the transplant recipients reported the following utilization of coping strategies (Table 8): Planful Problem-Solving, Positive Reappraisal, Self-Controlling, Confrontive Coping, Distancing, Seeking Social Support, Accepting Responsibility, and Escape-Avoidance.

Persons with rheumatoid arthritis reported the following use of coping interventions, again in descending order of frequency: Planful Problem-Solving, Self-Controlling, Positive Reappraisal, Escape-Avoidance, Accepting Responsibility, Distancing, Seeking Social Support, and Confrontive Coping.

Scores on the adjustment domains (Table 9) also used a four-point scale in which 0 reflected no difficulty and 3 represented significant difficulty. The domain with the healthiest level of adjustment is reported first and is followed by domains reporting increased distress.

The results for the transplant recipients were Extended Family Relationships, Health-Care Orientation, Social Environment, Domestic Environment, Psychosocial Distress, Sexual Relationship, and Vocational Environment. Again, going from area of best adjustment to least adjustment, the order for the arthritis patients was Extended Family Relationships, Health-Care Orientation,

Table 8. Coping strategies of sample population.

	Mean		Standard Deviation	
	R.A.	C.T.*	R.A.	C.T.
Planful Problem-Solving	1.90	1.74 <sub>1</sub>	.599	.581
Self-Controlling	1.86	1.73 <sub>2</sub>	.614	.603
Positive Reappraisal	1.83	1.74 <sub>1</sub>	.604	.581
Escape-Avoidance	1.78	1.46 <sub>7</sub>	.717	.566
Accepting Responsibility	1.77	1.54 <sub>6</sub>	.666	.610
Distancing	1.65	1.58 <sub>4</sub>	.619	.685
Seeking Social Support	1.62	1.55 <sub>5</sub>	.676	.617
Confrontive Coping	1.56	1.62 <sub>3</sub>	.607	.578

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R.A. = rheumatoid arthritis patients

C.T. = cardiac transplant patients

0 = "does not apply and/or not used"

1 = "used somewhat"

2 = "used quite a bit"

3 = "used a great deal"

\*Subscripts reflect rank order in this column.

Table 9. Adjustment domain difficulties of sample population.

	Mean		Standard Deviation	
	R.A.	C.T.*	R.A.	C.T.
Extended Family Relationships	.530	.262 <sub>1</sub>	.594	.382
Health-Care Orientation	.837	.562 <sub>2</sub>	.451	.392
Sexual Relationship	.923	.923 <sub>6</sub>	.846	1.310
Domestic Environment	.935	.712 <sub>4</sub>	.516	.461
Psychosocial Distress	1.116	.818 <sub>5</sub>	.755	.552
Social Environment	1.119	.628 <sub>3</sub>	.717	.569
Vocational Environment	1.220	1.680 <sub>7</sub>	1.110	2.040

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R.A. = rheumatoid arthritis patients

C.T. = cardiac transplant patients

0 = no difficulty

1 = a little difficulty

2 = moderate difficulty

3 = substantial difficulty

\*Subscripts reflect rank order in this column.

Sexual Relationship, Domestic Environment, Psychosocial Distress, Social Environment, and Vocational Environment.

Discriminant analysis was done to determine if adjustment to illness scores could accurately predict whether an individual was a cardiac transplant patient or a person with arthritis. Five adjustment domains (social environment,  $p = .0002$ , health-care orientation,  $p = .0018$ , extended family relationships,  $p = .005$ , domestic environment,  $p = .0158$ , and psychological distress,  $p = .0168$ ) were useful in predicting group membership. Using discriminant analysis of psychosocial adjustment to illness scores, it was possible to predict 71% of the cardiac transplant patients and 66.1% of the rheumatoid arthritis sufferers. The percentage of "grouped" cases correctly classified was 68.6%.

Discriminant analysis was also performed to ascertain whether medical condition could be accurately predicted by coping strategies used. Significance levels were marginal with only accepting responsibility significant at the .05 level. Significance levels were as follows: accepting responsibility,  $p = .041$ ; planful problem-solving,  $p = .075$ ; positive reappraisal,  $p = .0711$ ; and confrontive coping,  $p = .088$ .

Accepting responsibility, planful problem-solving, positive reappraisal, and confrontive coping were somewhat

useful in predicting group membership. Using these four coping strategies, it was possible to predict 63.6% of the transplant recipients and 65.9% of the arthritis patients for 64.71% of the "grouped" cases.

#### Research Question 2

This question asked how cardiac transplant recipients are similar to and different from patients with chronic rheumatoid arthritis regarding coping behavior and adjustment to illness. Data which may relate to responses about coping behavior and adjustments to illness pertain to frequency of symptoms or medication side effects and related stressfulness of these symptoms.

There are differences between the two populations in the reported frequency (Table 10) and stressfulness (Table 11) of symptoms or medication side effects. Symptoms/side effects occur at least two to three times per week in 76.2% of persons with arthritis and in 56% of the transplant recipients. And 84.1% of persons with arthritis versus 54.5% of transplant recipients find these symptoms/side effects to be moderately to extremely stressful. In considering the degree of control these individuals believe they have over the long-term course of their physical health, 63% of the transplant recipients versus 32.8% of persons with arthritis anticipate substantial to extreme amounts of control.

Table 10. Frequency of symptoms and/or medication side effects: Cardiac transplant (C.T.) and rheumatoid arthritis (R.T.).

Value Label	C.T.		R.A.	
	Frequency	Percent	Frequency	Percent
Almost Constant	21	31.8	38	60.3
2-3 Times/Day	5	7.6	5	7.9
1 Time/Day	8	12.1	3	4.8
2-3 Times/Week	3	4.5	2	3.2
1 Time/Week	1	1.5	0	0.0
2-3 Times/Month	3	4.5	1	1.6
1 Time/Month	1	1.5	0	0.0
Seldom	22	33.3	9	14.3
Missing	2	3.0	5	7.9
Total	66	100.0	63	100.0



Table 11. Stress related to symptoms/medication side effects: Cardiac transplant (C.T.) and rheumatoid arthritis (R.T.).

Value Label	C.T.		R.A.	
	Frequency	Percent	Frequency	Percent
Extremely Stressful	2	3.0	5	7.9
Very Stressful	5	7.6	14	22.2
Quite Stressful	8	12.1	11	17.5
Moderately Stressful	21	31.8	23	36.5
Somewhat Stressful	1	1.5	2	3.2
A Little Stressful	4	6.1	1	1.6
Slightly Stressful	7	10.6	1	1.6
Not at all Stressful	18	27.3	6	9.5
Total	66	100.0	63	100.0

A t-test done to assess the difference between overall frequency of coping strategies utilized showed no significant difference between persons with arthritis and transplant recipients. The total scores reflecting intensity of coping response did not differ between groups.

To assess differences in coping and adjustment by medical condition, individual items on each questionnaire were compared by medical condition using a Pearson chi-square test and a .05 level of significance. Of the 65 items on the coping questionnaire, only 4 showed significant differences between the two diagnostic groups. Responses for Item 5, "I bargained or compromised to get something positive from the situation," differed by medical condition at a .012 level of significance. Persons with arthritis used this strategy more than transplant recipients. However, this item does not factor load to any of the nine major coping styles.

Item 7, "I tried to get the person responsible to change his or her mind," is a coping response used more by transplant recipients than arthritis patients (.025 level of significance). This behavior factor loads for confrontive coping.

Item 37, "I maintained pride and kept a stiff upper lip," was reported more often (at a .006 level of significance) by persons with arthritis. However, this

strategy does not factor load into the identified methods for coping.

Item 48, "I drew on my past experiences; I was in a similar situation before," had between-groups significance at the .042 level. Persons with arthritis used this coping intervention more often than transplant recipients. This item contributed to the coping strategy of planful problem-solving.

The hypothesis that heart transplant recipients would use more avoidant coping styles than would persons with rheumatoid arthritis was not supported.

Of the 46 items comprising the Psychosocial Adjustment to Illness Scale (PAIS), 18 responses differed significantly by medical condition. Item 4 in Section 1 asked about treatment received by medical staff. Transplant patients reported a significantly (.042) more positive response. Item 5, Section 1, asked whether the individual believed they would overcome the illness and return to being their "old self." Significantly (.00001) more transplant patients believed this would occur than did patients with arthritis. Section 1, Item 7, asked about trust in medical staff to direct health treatment. Transplant recipients believed their doctors were more able to direct their treatment than did persons with arthritis

(.048 significance level). These three items pertained to the adjustment domain of health-care orientation.

Section 2 of the PAIS-SR included vocational environment. Responses to Items 1 and 2 differed significantly by medical diagnosis (.006 and .0007, respectively). Item 1 asked about the extent to which the health condition had interfered with the patient's ability to do his or her job. Transplant recipients more frequently reported either no problems or total inability to work. Persons with arthritis more often reported "some" to "serious" problems in doing their job. In Item 2, arthritis patients reported more problems with physical performance of job tasks than did transplant recipients.

Section 3 contained questions pertaining to the domestic environment. Four of the eight items had responses which were significantly different by medical condition. Persons with arthritis reported (.00004 significance level) that their health condition interfered more with work and duties around the house. Transplant recipients reported (.015 significance level) that family members were more able to shift duties to help with problems in housework. Transplant recipients also felt (.003 significance level) more strongly that help was provided when needed. Arthritis patients reported (.0001 significance level) more physical disability secondary to

health condition. Transplant recipients reported (.016 significance level) more financial difficulties related to health condition.

None of the items included under sexual relationship (Section 4) were significantly different by medical condition.

Section 5 pertained to extended family relationships. In Item 3, transplant recipients reported more (.0006 significance level) availability of physical help from extended family.

Social environment was the theme of Section 6. In Item 1, transplant recipients reported more (.019 significance level) interest in leisure activities and hobbies. In Item 2, they also reported (.002 significance level) greater involvement in leisure-time activities, and in Item 3 (.029 significance level), more interest in leisure-time activities with family. Item 4 showed transplant recipients (.0008 significance level) participating more in leisure-time activities with family. Responses to Item 6 reflected that transplant recipients also participated more in social activities (.007 significance level).

Psychological distress was the final PAIS-SR domain. Two items differed significantly. Item 2 suggested that persons with arthritis experienced more feelings of

sadness, depression, and hopelessness (.046 significance level), while Item 5 reflected that transplant recipients worried more about their health condition or other matters (.002 significance level).

Summary scores for coping strategies and adjustment domains were also analyzed for differences between medical illness groups. Comparing summary scores of coping strategies, there were no significant differences between the two populations.

Comparing summary scores of adjustment domains, three of the seven domains differed significantly by medical diagnosis. Using chi-square calculations, health-care orientation scores differed significantly by medical condition ( $p = .044$ ). Rheumatoid arthritis patients had significantly more problems in the adjustment domain of health-care orientation.

The second adjustment domain that differed significantly between medical conditions was extended family relationships ( $p = .035$ ). Again, persons with arthritis reported more difficulties in extended family relationships than did transplant recipients.

Social environment also differed significantly by medical condition ( $p = .038$ ). Persons with arthritis reported poorer adjustment in this area than did the transplant recipients.

A third hypothesis was that transplant recipients would report less control over both their day-to-day symptoms/medication side effects and their long-term physical health than would persons with arthritis. This hypothesis was not supported.

As regards personal control over daily status, 51.5% of the transplant recipients reported substantial to extreme control compared with 30.2% of the arthritis group. However, 30.3% of the transplant recipients reported slight to absolutely no control versus 19% of the arthritis group. As regards anticipated personal control over long-term health status, the transplant recipients expect to have more control than persons with arthritis. A full 62.1% of the transplant recipients anticipate substantial to extreme control versus 31.7% of persons with arthritis. And in the transplant group, only 12.1% anticipate slight to absolutely no control versus 20.6% of persons with arthritis.

### Research Question 3

This question inquired about the relationship between ways of coping and psychosocial adjustment to illness within each subject group and as a total chronic illness group. Pearson correlation coefficients were calculated to assess the relationships between coping styles and psychosocial adjustment within each medical diagnostic

group. A .05 level of significance was used in interpreting the results.

The significant correlation coefficients for the cardiac transplant recipients are discussed first. As distancing (cognitive efforts to detach oneself) increased, there was more distress reported in the area of extended family relationships ( $r = .28, p = .013$ ). As the transplant recipients reported more self-controlling strategies (efforts to regulate own feelings and actions), their health care orientation scores improved ( $r = - .23, p = .032$ ). A self-controlling coping style was also correlated with improved extended family relationships ( $r = - .22, p = .045$ ).

The coping scale for "seeking social support" (SSS) (efforts to seek informational and emotional support) was significantly correlated with health-care orientation (HCO) ( $r = - .23, p = .045$ ). As SSS increased, there was less distress reported in HCO. Seeking social support had a similar relationship with extended family relationships ( $r = - .31, p = .010$ ).

Among transplant recipients, planful problem-solving (PPS) was significantly related to adjustment in one's social environment ( $r = - .34, p = .004$ ). As PPS increased, social environment difficulties decreased. PPS



had a similar correlation with psychological distress ( $r = - .23, p = .037$ ).

Next the Pearson correlation coefficients for the coping styles and psychosocial adjustment domains of the persons with rheumatoid arthritis are described. The only correlation that involved the same two variables and direction of relationships with both medical groups was the correlation between distancing and extended family relationships ( $r = .35, p = .005$ ). Among persons with arthritis, as distancing increased, so did distress with extended family relationships.

With two other sets of variables, the same variables had a significant relationship, but the direction of the relationship differed between the transplant recipients and the persons with arthritis. In the arthritis group, self-controlling strategies were correlated ( $r = .31, p = .009$ ) with more problems in the area of extended family relationships. Seeking social support was also correlated ( $r = .24, p = .042$ ) with more difficulties with extended family relationships.

There were also relationships which were significant among the arthritis group but not among the transplant recipients. For persons with arthritis, distancing had a significant correlation ( $r = .32, p = .010$ ) with problems in one's vocational environment. Distancing was also

correlated ( $r = .27$ ,  $p = .028$ ) with problems in the domestic environment.

Within the arthritis group, the escape-avoidance coping strategy (wishful thinking, efforts to escape the problem) was significantly correlated with problems in many adjustment domains. Escape-avoidance (EAV) was correlated ( $r = .33$ ,  $p = .011$ ) with difficulties in the vocational environment, with problems in the domestic environment ( $r = .28$ ,  $p = .023$ ), with increased distress in extended family relationships ( $r = .38$ ,  $p = .003$ ), with problems in the social environment ( $r = .34$ ,  $p = .008$ ), and with increased psychological distress ( $r = .29$ ,  $p = .020$ ).

Persons with arthritis reported a significant correlation ( $r = .37$ ,  $p = .002$ ) between self-controlling coping and problems with sexual relationships. This group also had a significant correlation ( $r = .29$ ,  $p = .026$ ) between the strategy of accepting responsibility (acknowledging one's own role in the problem) and problems in extended family relationships. Their use of the planful problem-solving coping strategy (problem-focussed efforts to alter the situation) was correlated ( $r = .33$ ,  $p = .007$ ) with problems in sexual relationships.

Finally, for persons with arthritis, positive reappraisal was significantly correlated with adjustment in two domains, health-care orientation ( $r = - .1657$ ,  $p =$

.045) and extended family relationships ( $r = .1867$ ,  $p = .028$ ). Increased use of positive reappraisal went along with improved adjustment in health-care orientation and poorer reported adjustment in extended family relationships.

The hypothesis that among patients with rheumatoid arthritis the correlation between active coping strategies and psychosocial adjustment would be greater than the correlation between avoidant coping styles and psychosocial adjustment was not supported. Avoidance coping was linked to poorer adjustment among persons with arthritis. The related hypothesis that among heart transplant recipients the correlation between avoidant coping and psychosocial adjustment would be greater than the correlation between active coping and psychosocial adjustment was also not supported. Avoidant coping had only one significant negative correlation with adjustment in the transplant group, and active coping had three significant positive correlations with adjustment areas.

Pearson correlation coefficients were used to analyze the relationship between ways of coping and psychosocial adjustment to illness in the total population (see Table 12). Four coping strategies were found to be significantly correlated with adjustment domains. Confrontive coping had a significant correlation ( $r = - .1837$ ,  $p = .026$ ) with

**Table 12. Significant correlations between coping strategies and adjustment domains.**

Coping Strategy	Arthritis Adjustment Domain	Cardiac Transplant Adjustment Domain	Combined Group Adjustment Domain
Distancing	↓ Domestic Environment ↓ Vocational Environment ↓ Extended Family Relationships	↓ Extended Family Relationships	↓ Domestic Environment ↓ Vocational Environment ↓ Extended Family Relationships
Escape-Avoidance	↓ Vocational Environment ↓ Extended Family Relationships ↓ Social Environment		↓ Domestic Environment ↓ Extended Family Relationships ↓ Social Environment ↓ Psychological Distress
Self-Controlling	↓ Sexual Relationships ↓ Extended Family Relationships	↑ Health Care Orientation ↑ Extended Family Relationships	
Seeking Social Support	↓ Extended Family Relationships	↑ Health Care Orientation ↑ Extended Family Relationships	
Accepting Responsibility	↓ Extended Family Relationships		↓ Extended Family Relationships ↓ Psychological Distress
Planful Problem Solving	↓ Sexual Relationships	↑ Social Environment	
Positive Reappraisal	↑ Health Care Orientation		
Confrontive Coping			↑ Health Care Orientation

↑ increased adjustment

↓ decreased adjustment

health-care orientation. As confrontive coping increased, so did level of adjustment regarding health-care orientation.

Overall, distancing was significantly correlated with three adjustment domains: vocational environment ( $r = .2045$ ,  $p = .016$ ), domestic environment ( $r = .1823$ ,  $p = .027$ ), and extended family relationships ( $r = .3121$ ,  $p = .000$ ). As distancing increased, adjustment in all three domains decreased.

Accepting responsibility had significant correlations with two adjustment domains, extended family relationships ( $r = .1847$ ,  $p = .038$ ) and psychosocial distress ( $r = .2468$ ,  $p = .009$ ). As persons reported increased coping through accepting responsibility, they also reported increased difficulty with extended family and increased psychosocial distress.

Escape-avoidance had four adjustment domains with significant correlations. The adjustment domains were (1) domestic environment ( $r = .2180$ ,  $p = .015$ ), (2) extended family relationships ( $r = .3438$ ,  $p = .000$ ), (3) social environment ( $r = .3102$ ,  $p = .001$ ), and (4) psychosocial distress ( $r = .3097$ ,  $p = .001$ ). As persons reported increased utilization of escape-avoidance, they also reported poorer adjustment in these four areas.

The hypothesis that frequency of symptoms and medication side effects and related stress would be more predictive of psychosocial adjustment than medical diagnosis was partially supported (Table 13). Pearson chi-square was used to test this hypothesis. There were eighteen items on the psychosocial adjustment to illness questionnaire whose responses were dependent on degree of illness-related stress. Seventeen adjustment questionnaire items had responses significantly (.05) dependent on medical diagnosis group. Five adjustment items had responses which were dependent on frequency of symptoms and medication side effects.

The adjustment domain of Health Care Orientation was comprised of eight items. Responses to two items depended on symptom frequency, two items depended on related degree of stress, and two items depended on medical diagnosis group.

The second adjustment domain, which has six items, was Vocational Environment. The responses to three of these items depended on perceived stress, two items were dependent on medical diagnosis, and one item was dependent on symptom frequency.

The third adjustment domain, Domestic Environment, contains eight items. Responses to two items depended on

Table 13. Adjustment domains by symptom frequency, degree of stress, and medical diagnosis.

<u>Adjustment Domains</u>	<u>Frequency of Symptoms or Medication Side Effects</u>	<u>Amount of Stress Related to Symptoms or Medication Side Effects</u>	<u>Medical Diagnosis</u>
Health Care Orientation	2	2	2
Vocational Environment	1	3	2
Domestic Environment	2	3	5
Sexual Relationships	0	0	0
Extended Family Relationships	0	2	1
Social Environment	0	2	5
Psychological Distress	0	6	2
	—	—	—
Total	5	18	17

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Note: Figures in each column indicate the number of items from each adjustment domain with responses significantly dependent on symptom frequency, degree of stress, or medical diagnosis.

symptom frequency, three items depended on amount of stress, and five items depended on medical diagnosis.

The fourth domain is Sexual Relationships, and none of the items depended on frequency of symptoms, stress, or medical diagnosis.

Extended Family Relationships is the fifth domain. No items were dependent on symptom frequency, two items depended on stress, and one item depended on medical diagnosis.

The sixth domain is Social Environment. No items were dependent on symptom frequency, two items were dependent on stress, and five items were dependent on medical diagnosis.

The final domain is Psychological Distress. No items were dependent on symptom frequency, six items were dependent on stress, and two items were dependent on medical diagnosis.

Overall, stress and medical diagnosis seemed to influence responses on the psychosocial adjustment questionnaire to a greater extent than did symptom frequency.

#### Research Question 4

This question asked: Do specific coping styles seem to be linked to adjustment in certain life domains? Multiple regression analysis was used to assess which coping strategies contributed significantly to variation in



adjustment to illness domains. The adjustment domain, health-care orientation, was used as the dependent variable in a stepwise regression. With a correlation of .255 and a significance level of .0404, accepting responsibility was found to explain 6.5% of the variation in health-care orientation.

When vocational environment was the dependent variable, distancing was found to be a significant contributor. With a correlation of .251 and a .0439 level of significance, 6.3% of the variation in vocational environment adjustment could be explained by variation in use of distancing as a coping strategy.

When the effect of distancing on vocational environment adjustment was held constant, planful problem-solving became a significant contributor. Planful problem-solving had a .018 level of significance, and variance in planful problem-solving explained 12% of the variance in vocational environment.

Multiple regression analysis using domestic environment as the dependent variable resulted in escape-avoidance being significantly powerful in explaining variance. With a correlation of .322 and a significance level of .0088, variance in escape-avoidance explained 10% of the variance in domestic environment.

Using sexual relationships as the dependent variable, regression analysis resulted in none of the coping strategies as significant contributors of variance.

With extended family relationships as the dependent variable, escape-avoidance had a correlation of .354, a significance of .0039, and contributed to 12.5% of the variance in extended family relationships.

The variance in social environment was significantly explained by variance in escape-avoidance. The correlation was .438, the significance level was .0003, and 19% of the variance in social environment adjustment was explained by variance in escape-avoidance.

The hypothesis related to Research Question 4 was that persons with chronic illness who used the coping strategies of problem-focused coping, seeking social support, and positive reappraisal would have higher levels of psychosocial adjustment to illness than persons who relied heavily on the coping strategies of escape-avoidance and distancing.

Based on findings in the literature (Pearlin & Schooler, 1978; Noble & Hamilton, 1983; Weisman & Worden, 1976-77), escape-avoidance and distancing were hypothesized to be correlated with poorer adjustment scores and seeking social support, positive reappraisal, and planful problem-solving with better adjustment scores. Thirty individuals

were identified with distancing scores of 1 or 2 (low), and 32 persons were identified with distancing scores of 6-13 (high). Similarly, 29 persons were rated as low (1-2) on escape-avoidance, and 31 persons were rated as high (8-24). Twenty-seven persons rated low (1-4) on positive reappraisal, and 28 persons rated high (11-19). On seeking social support, 21 persons rated low (1-2), and 19 rated high (10-18). For positive problem-solving, 24 individuals rated low (1-4), and 25 rated high (12-17).

Individuals were then identified who were either consistently high or low in the combined coping styles escape-avoidance/distancing and seeking social support/positive reappraisal/planful problem-solving. Eleven persons scored low on escape-avoidance/distancing, and 14 persons scored high. Twelve persons scored low on seeking social support/positive reappraisal/planful problem-solving, and nine persons scored high.

Analysis of variance results showed that persons who frequently cope through escape-avoidance/distancing vary significantly (.0061) from the other three groups relative to their domestic environment. The escape-avoidance/distancing high group also differed from the other three groups ( $p = .0109$ ) relative to extended family relationships. Domestic environment and extended family relationships were the only two adjustment domains with

significant relationships to what the literature suggests are positive and negative coping styles.

The coping strategy of accepting responsibility is positively correlated with increased psychosocial distress and problems with extended family relationships. Increased utilization of escape-avoidance is correlated with problems in the areas of domestic environment, extended family relationships, social environment, and psychosocial distress.

Persons with rheumatoid arthritis or those who have had a cardiac transplant who rely heavily on both escape-avoidance and distancing as ways of coping reported significant levels of difficulty in the areas of domestic environment and extended family relationships.

#### Discussion of Research Question 1

##### Coping Strategies

Research Question 1 asks about what coping patterns and adjustment levels each diagnostic group report. Table 8 (p. 87) contains data on what coping patterns were used by each medical diagnostic group. The patterns of coping mechanisms were similar for both groups, although the mean scores for coping strategies were somewhat higher in the arthritis group.

For persons with arthritis, in descending order of frequency, the coping strategies used were planful problem solving, self-controlling, positive reappraisal, escape-avoidance, accepting responsibility, distancing, seeking social support, and confrontive coping.

For persons with cardiac transplants, again in descending order of frequency, coping patterns were planful problem solving, positive reappraisal, self-controlling, confrontive coping, distancing, seeking social support, accepting responsibility, and escape-avoidance.

That planful problem solving tops the list is consistent with several authors who have done research on coping and reported on the importance of taking some direct actions as a coping strategy (Moos, 1976, 1986; Siddle, Moos, Adams, & Cody, 1969; Stone & Neale, 1984).

This study's finding of the relative less importance of the coping strategy of seeking social support is inconsistent with what other authors report. Several authors cite social support as important to coping (Dimsdale, 1976; Moos, 1976; Moos, 1986; Siddle, Moos, Adams, & Cody, 1969; Stone & Neale, 1984). Robbins and Tanck (1978) found that "seeking social support" was the factor that loaded strongest for decreasing tension in daily living. In the current study, seeking social support

ranked seventh of eight coping strategies of the arthritis group and sixth of eight for the transplant group.

In the literature, information seeking is another frequently reported coping strategy which is reported to have a positive impact on emotional well being and a sense of control (Felton & Revenson, 1984; Moos, 1986). The Ways of Coping Questionnaire does not contain a subsection on information seeking. Questions within "Seeking Social Support" come closest to inquiring about information seeking. The items are "talked to someone to find out more about the situation" and "I got professional help." Thus, although the literature contains numerous studies which report an impact of information-seeking behavior relative to chronic illness, the tools used in this study do not allow a valid analysis of the effect of information seeking as a coping strategy.

#### Adjustment Domains

Adjustment domains were rated on a scale of 0-3, with zero meaning "no difficulty" and three meaning "substantial difficulty." Table 7 contains data about each population's adjustment to illness domain scores.

For persons with arthritis going from best to poorest area of psychosocial adjustment, the domains are extended family relationships, health care orientation, sexual

relationship, domestic environment, psychosocial distress, social environment, and vocational environment.

For transplant recipients, again from best to poorest adjustment arenas, the results were extended family relationships, health care orientation, social environment, domestic environment, psychosocial distress, sexual relationships, and vocational environment.

Among persons with arthritis, communication and relationships with extended family were the areas of best adjustment. There is a difference of .690 between the mean score of the best area of adjustment (extended family relationships) and the mean score of the area of least adjustment (vocational environment). This suggests that while there is a difference between the levels of adjustment in the different domains, the differences are not large.

Within the cardiac transplant group, extended family relationships was also the area of best adjustment. Within the transplant group there was a difference of 1.418 between the mean score of area of best adjustment (extended family relationships) and the mean score of area of least adjustment (vocational environment). However, in the transplant group there may be unique factors which artificially affect employment status. Several respondents and the transplant coordinators mentioned that our medical

financial system impacts on their employability. Ongoing medical treatment post-transplant is expensive, and some transplant recipients who might otherwise be able to work have chosen to take medical disability to become Medicare eligible.

If one eliminates the transplant mean score for vocational environment, the spread between remaining scores is .661, suggesting a variance between adjustment domains similar to that of the arthritis group.

Because a heart transplant is a dramatic resurrection from pending death, it was hypothesized that transplant recipients would utilize more externally focused and passive coping strategies than the arthritis group. This hypothesis was not supported. The means of the coping strategies used by the two illness groups did not differ significantly. When discriminant analysis was used to attempt to predict medical diagnostic group by coping strategies, only accepting responsibility met the .05 level of significance criteria. Accepting responsibility was utilized more by the arthritis group and though internally focused, does have a passive quality.

#### Discussion of Research Question 2

Research Question 2 asked how transplant recipients were similar to and different from persons with arthritis regarding coping behaviors and adjustment to illness. It



was hypothesized that there would be no differences in the number of coping styles used between disease processes. This hypothesis was supported by the data. Although the arthritis group reported a slightly increased intensity of coping strategy utilization, there was no statistical difference in the mean scores of coping mechanisms by group.

A second hypothesis was that persons with arthritis would use more active coping strategies than the transplant recipients. This was not supported by the study's data.

The results of this study show that very similar coping patterns were used by persons with arthritis and the transplant recipients. The ranked order of utilization of coping strategies is almost identical between the two diagnostic groups (see Table 8). Statistically there was no difference between the coping styles of persons with arthritis and transplant recipients.

Felton, Revenson, and Hinricksen (1984), who studied three different chronic illnesses, also found that particular diseases were not linked to particular coping styles. In the current study, although four "ways of coping" items differed significantly between illness groups, the overall frequency of coping strategies showed no significant difference between persons with arthritis

and transplant recipients. Coping strategies were the same across illnesses.

Adjustment domains, however, did vary significantly by medical diagnosis. Persons with rheumatoid arthritis reported more difficulty in the area of health care orientation. Specifically, persons with arthritis report less satisfaction with the treatment they have received from their doctors and medical staff. They had less confidence in their physicians' ability to direct their health care. The arthritis group was more apt to describe themselves as "worn out" by their health condition and was less optimistic about the probability of ever returning to their "old selves."

Several factors may be pertinent in consideration of the difference between the two illness groups relative to health care orientation. Persons with arthritis were older (mean age 63 years) than the transplant recipients (mean age 53 years) and may thus feel more "worn out" and less hopeful about returning to their "old selves."

The two illnesses also differ in significant ways. Arthritis tends to be a progressive, deforming condition which attacks multiple joints (Harris, 1981) and for which there is no known cure (Shumacher, 1975).

Cardiac disease can also be progressive and debilitating. However, because of the nature of the

intervention used in cardiac transplant, the transplant recipients may, not surprisingly, have a different perception of their medical care. The rheumatologist has probably been a comrade in an up and down battle against pain and debilitation. In comparison, the cardiac transplant team has forestalled certain death, and cardiac transplantation may bring near return to one's prior abilities. Differences in health care orientation may largely be explained by differences in the two illness experiences and what the health teams have been able to deliver regarding thwarting the progression of disease.

Persons with arthritis also report more frequent symptoms or medication side effects and more stress related to their symptoms. This reported difference in experienced stress and symptom severity may explain part of the difference in health care orientation.

The adjustment domain of extended family relationships differed significantly across diagnostic groups. Persons with arthritis more often reported that physical help was needed but not supplied from family members outside their household. They were more apt to report poor relationships with extended family and less contact and less interest in contact with extended family members.

Factors which may explain the increase in unmet need for physical help in the arthritis group include both

gender and age. More than three-quarters of the persons with arthritis are female versus 15% of the transplant recipients. And as stated earlier, the arthritis group was ten years older (mean age 63 years). Also, not quite as many of the arthritis group (68.9%) are married as compared with the transplant group (77.3%).

The issues regarding quality of relationships with extended family and interest in contact with extended family and why the illness groups would differ are more difficult to explain. Dell Orto (1984) writes about the feeling of powerlessness that family members often experience when a loved one is ill. It is possible this powerless feeling may also be felt by extended family members, putting a strain on the relationship. Craig and Edwards (1983) write about how an ill person's prolonged dependency may exhaust family members' coping abilities. Over time extended family members may become less involved and less available. While it is unclear as to why this would occur significantly more often for individuals with arthritis, it may occur more often for elderly versus middle-aged persons.

Social environment was the third adjustment domain that differed significantly across medical diagnosis. Social environment addresses interest and participation in leisure activities done individually with family or with

larger social groups. Persons with arthritis scored significantly lower in all areas of social activities.

Employment status is very similar for persons with arthritis and cardiac transplant recipients, suggesting that available time for leisure activities would be similar for both groups. Symptoms/side effects frequency and related stress are greater for persons with arthritis. This factor may limit their enthusiasm for leisure activities.

Another hypothesis was that the transplant recipients would report less control over both their day-to-day symptoms/medication side effects and their long-term physical health. This hypothesis was also not supported.

The transplant recipients had a bimodal response pattern regarding day-to-day symptoms, with more than half reporting substantial to extreme control and almost a third reporting slight to no control (Table 14). This group was divided between those who were doing well in this dimension and those who were experiencing significant problems. In contrast, the arthritis group's response curve was much more like a normal distribution (Table 14). Almost two-thirds claimed some to substantial control. Extremes regarding control of daily symptoms were not commonly reported by persons with arthritis.

Table 14. Personal control over daily symptoms and/or medication side effects: Cardiac transplant (C.T.) and rheumatoid arthritis (R.A.).

Value Label	C.T.		R.A.	
	Frequency	Percent	Frequency	Percent
Absolutely No Control	13	19.7	4	6.3
Slight Control	7	10.6	8	12.7
A Little Control	2	3.0	1	1.6
Some Control	8	12.1	12	19.0
Moderate Control	2	3.0	16	25.4
Substantial Control	11	16.7	11	17.5
A Large Amount of Control	9	13.6	3	4.8
Extreme Amount of Control	14	21.2	5	7.9
Missing	0	0.0	3	4.8
Total	66	100.0	63	100.0

This same pattern was not upheld when respondents reported on anticipated long-term control over physical health (Table 15). In this dimension, the transplant recipients were clearly more optimistic, with twice as many (nearly two-thirds) expecting substantial to extreme control. Similarly, almost twice as many (one-fifth) of the persons with arthritis anticipated slight to no control over long-term health. The arthritis group may have experienced more years of disappointments in struggling with physical health issues and, understandably, were less optimistic about control of health in the future.

#### Discussion of Research Question 3

This question asked: What are the relationships between ways of coping and psychosocial adjustment within the two groups independently and as a total chronic illness group?

#### Rheumatoid Arthritis Relationships: Ways of Coping and Psychosocial Adjustment to Illness

Within the arthritis group, there were five coping strategies that were significantly correlated with difficulty in the area of extended family relationships. The coping strategies were distancing, self-controlling, seeking social support, positive reappraisal, and accepting responsibility. Of these, two are strongly significant

Table 15. Personal control over long-term physical health: Cardiac transplant (C.T.) and rheumatoid arthritis (R.A.).

Value Label	<u>C.T.</u>		<u>R.A.</u>	
	Frequency	Percent	Frequency	Percent
Absolutely No Control	3	4.5	5	7.9
Slight Control	5	7.6	8	12.7
Some Control	11	16.7	8	12.7
Moderate Control	5	7.6	20	31.7
Substantial Control	13	19.7	12	19.0
A Large Amount of Control	14	21.2	5	7.9
Extreme Amount of Control	14	21.2	3	4.8
Missing	1	1.5	2	3.2
	<hr/>	<hr/>	<hr/>	<hr/>
Total	66	100.0	63	100.0



(distancing,  $p = .005$ , and self-controlling,  $p = .009$ ), two are moderately significant (accepting responsibility,  $p = .026$ , and positive reappraisal,  $p = .028$ ), and one is marginally significant (seeking social support,  $p = .042$ ).

Conceptually, the two variables with strong significance seem easiest to understand. Distancing involves emotional detachment from the significance of the situation. Self-controlling describes efforts to regulate one's feelings. It seems understandable that persons who tended to contain their feelings might report less closeness with extended family.

Accepting responsibility refers to acknowledging one's own role in the problem and includes the theme of trying to put things right. However, the items in the accepting responsibility scale also imply self-criticism and feelings of guilt. It is unclear why there would be a relationship between accepting responsibility and extended family relationships.

That there also was a significant, though slight, correlation between seeking social support and problems with extended family relationships seems confounding, and no explanation for this correlation is offered.

Among persons with arthritis, distancing also was paired with problems in the vocational environment and the domestic environment. The link between being detached and

having problems with communication and relationships at home seems understandable. The relationship between distancing and problems at work seem less obvious.

With persons with arthritis, escape-avoidance was correlated with problems in vocational environment, extended family relationships, social environment, and with increased psychological distress. Two items in the escape-avoidance scale pertain to relationships and could relate to the difficulties with extended family, socialization, and possibly work. The items are "avoided being with people in general" and "took it out on other people." The scale in general measures a tendency to deny the difficult situation. Persons relying on this as a coping strategy may be feeling overwhelmed by the situation and unable to competently manage what they are facing.

There are also items that are suggestive of depression and substance abuse which may relate to the correlation with psychological distress. These items are "slept more than usual" and "tried to make myself feel better by eating, drinking, smoking, using drugs or medication."

Two coping strategies, self-controlling and planful problem solving, were tied to problems in sexual relationships in the arthritis group. Self-controlling describes efforts to regulate one's feelings and actions, and the scale includes the items "I tried to keep my

feelings to myself" and "kept others from knowing how bad things were." It is possible that a self-controlling person may be less communicative with one's partner which could affect one's sexual relationship.

Planful problem solving relates to taking deliberate problem-focused actions, and this researcher offers no explanation as to the correlation between problem-solving behavior and sexual relationship problems.

Finally, for persons with arthritis, positive reappraisal was correlated with healthy adjustment in the domain of health care orientation. Persons who reported a focus on personal growth and an attempt to create positive meaning in their situation described more positive attitudes regarding their medical treatment. It seems reasonable that persons focusing on personal growth within the context of chronic illness might be less critical of their medical care.

Cardiac Transplant Recipient Relationships: Ways of Coping and Psychosocial Adjustment to Illness

Four coping strategies were significantly correlated with adjustment domains among the transplant recipients. The strategies were distancing, self-controlling, seeking social support, and planful problem solving.

Among transplant recipients, the coping strategy of distancing was linked with problems with extended family

relationships. As in the arthritis group, it seems reasonable that persons who use emotional detachment to deal with stress may report less closeness with their extended family.

Self-controlling as a coping strategy was correlated with two positive adjustment outcomes in the transplant group. Health care orientation and extended family relationships improved as persons reported more frequent use of self-controlling coping. The items on the self-controlling scale describe coping through self-regulation and a "stiff upper lip" attitude. It is possible that persons who report that they "tried not to burn my bridges" and "tried not to act hastily" might be slower to criticize their medical care. Similarly, someone who dealt with their stress somewhat stoically might have fewer problems with extended family relationships.

Among transplant recipients, seeking social support was correlated with a positive health care orientation. As persons talked more with relatives or friends to share feelings and gain information, advice, and understanding, they reported improved attitudes towards their physicians and treatment, quality of information and more optimistic expectations about their health.

It was also found that as cardiac transplant recipients reported increased coping through seeking social

support that their adjustment in extended family relationships improved. They reported improved quality of relationships and interest in interacting with family. Both of these correlations seem intrinsically logical.

Planful problem solving correlated with improved interest and participation in leisure-time activities. It is feasible that including leisure/social activity in one's schedule could be part of a deliberate problem-focused approach to cope with stress.

#### Coping and Adjustment in Combined Chronic Illness Group

When results from persons with arthritis are combined with results from the cardiac transplant recipients, four coping strategies are significantly correlated with adjustment domains. The coping strategies are confrontive coping, distancing, accepting responsibility, and escape-avoidance.

In the Ways of Coping Scale, confrontive coping refers to aggressive efforts to alter the situation and suggests a degree of hostility and risk-taking. In the current study, confrontive coping was associated with better adjustment in the health care orientation domain. Robbins and Tanck (1978) found that taking direct action was an important component of coping. Felton and Revenson (1984) reported that confrontive approaches for dealing with illness were

correlated with positive adjustment. Similarly, Weisman and Worden (1976-77) found confrontation, which they describe as facing the facts about one's situation, to be a strategy of successful copers. Noble and Hamilton (1983) write about the need to express rage and hurt.

Health care orientation assesses patients' attitudes toward their own health care, the quality of information received, and the nature of the patient's expectations about his/her disorder.

The correlation between confrontive coping and health care orientation may suggest that when individuals are involved in their self-care and committed to take actions to improve their situation that they more actively collaborate with care providers and maintain more optimistic expectations regarding their treatment.

In the current study, distancing was the second coping strategy with significant correlations to adjustment domains in the combined group. As distancing increased, vocational environment, domestic environment, and extended family relationships deteriorated. In the Ways of Coping Questionnaire, distancing describes cognitive efforts to detach oneself in order to minimize the situation's significance.

While coping through distancing may be useful in containing otherwise overwhelming feelings, a reliance on

distancing may limit the use of other functional coping strategies. White (1976) reports that self-esteem is maintained by a sense of competency, and Miller (1983) states that positive self-concept comes with the understanding that the ability to manage the care of health problems resides within the self. In Frye's (1986) model of wellness behavior, the important variables are sense of control, level of self-confidence, and level of inner strength. Frye expounds on persons benefitting when they act as if they can influence their life events and states that risk-taking is an outcome of self-confidence. Felton and Revenson (1984) found information seeking to be a significant contributor to positive affect. A person who copes through distancing may not take an active role in self-care, which several authors cite as important in chronic illness (Counte, Bieliausha, & Pavlou, 1983; Weisman & Worden, 1976-77; Miller, 1983).

One might postulate that as a person relies more on distancing as a coping strategy that investment in job performance and career goals may diminish.

Distancing was also correlated with adjustment difficulties with communication and relationships both with immediate and extended family. One wonders whether persons who cope through distancing may be less open in their communication with family members when feeling vulnerable.

Accepting responsibility is the third coping strategy that had significant correlations with adjustment domain in the combined medical diagnoses group. Accepting responsibility was moderately significantly correlated with problems with extended family relationships and strongly correlated with psychological distress. Accepting responsibility in the Ways of Coping Questionnaire refers to acknowledging one's role in the problem and also suggests an intention to put things right. However, containing only four items, accepting responsibility is the briefest subscale. And the two items that factor load heaviest for accepting responsibility seem negativistic. These items are "criticized or lectured myself" and "realized I brought the problem on myself." A third item suggests acceptance of blame: "I apologized or did something to make up." So the items on the scale do not suggest a proactive, empowering quality of taking on responsibility for a situation but rather suggest a self-punitive or guilty position. With this understanding of the accepting responsibility subscale, it seems understandable that it would be associated with psychological maladjustment.

Escape-avoidance is the fourth coping strategy which was significantly correlated with adjustment domains in the combined study group. As persons reported more reliance on



escape-avoidance, they reported more difficulties in the areas of extended family relationships, domestic environment, psychological distress, and social environment.

Escape-avoidance describes wishful thinking and actions taken to escape or avoid the problem. Escape-avoidance as a coping style runs contrary to several coping mechanisms which are reported to improve adjustment: information seeking (Felton & Revenson, 1984), taking direct action (Robbins & Tanck, 1978), and seeking social support (Noble & Hamilton, 1983). Weisman and Worden (1976-77) found suppression to be linked with poor coping outcomes. The escape-avoidance items reflect avoidance of people, a passive approach to problems, and the possibility of substance abuse.

In the current study, persons who coped through escape-avoidance strategies reported more difficulty with communication and relationships in immediate and extended families, less satisfaction in their leisure interests and activities, and increased severity of dysphoric thoughts and feelings. It is reasonable that a person reporting frequent use of escape-avoidance would have problems with relationships and would report increased psychological distress.

### Factors Pertaining to Psychosocial Adjustment

A hypothesis related to Research Question 3 was that symptom frequency and associated stress would be stronger predictors of psychosocial adjustment than would medical diagnosis. In fact, it appears that adjustment may be more dependent on stress and diagnosis than symptom frequency. Stress was the most important factor in all domains but two. In Domestic Environment and Social Environment, diagnosis was more important than stress in contributing to item responses. Again, this points to differences between the arthritis and cardiac transplant groups regarding adaptation of the family unit in response to the patient's illness and the degree to which the individual has suffered constriction of social activities as a result of illness.

Another hypothesis was that among persons with rheumatoid arthritis, the correlation between active coping strategies and psychosocial adjustment would be greater than the correlation between avoidant coping and psychosocial adjustment. Among transplant recipients it was expected that the correlation between avoidant coping strategies and psychosocial adjustment would be greater than the correlation between active coping and psychosocial adjustment. This hypothesis was also not supported. In both groups, active coping was correlated with psychosocial adjustment.

#### Discussion of Research Question 4

This question asks whether specific coping styles are linked to adjustment in certain life domains. The hypothesis is that persons who cope using problem-focused strategies, seeking social support, and through positive reappraisal will have higher adjustment scores than persons who cope through distancing and escape-avoidance methods.

An attempt was made to compare the data from this study to what other authors have referred to as positive or negative coping.

Literature on coping has identified strategies as positive or negative depending on their association with favorable or dysfunctional outcomes. Social support is cited as associated with such positive qualities as positive health outcomes (Cohen & Wills, 1985), reduced emotional distress (Pearlin & Schooler, 1978), and high levels of well being (Schulz & Decker, 1985).

Problem-solving efforts are also associated with positive outcomes. Moos (1986) reports that analyzing information and considering alternative actions can restore a sense of control. Felton and Revenson (1984) report that taking direct action was correlated with positive adjustment.

Qualities inherent in Lazarus and Folkman's (1984) Positive Reappraisal coping strategy are also reported in

the literature. Feldman (1974) expounds on hope as a quality which can save a chronically ill person from becoming apathetic or depressed. Based on this information from the literature, seeking social support, planful problem solving, and positive reappraisal were clumped as "positive" coping strategies.

Weisman and Worden (1976-77) found that poor copers minimally acknowledge their illness. Cronkite and Moos (1984) report that men who use avoidant coping strategies were more depressed, had lower self-esteem, and consumed more alcohol. For purposes of comparing "positive" and "negative" strategies, Lazarus and Folkman's (1984) strategies of escape-avoidance and distancing were paired as negative coping strategies by this researcher.

In this study, persons were identified who scored high in all three positive areas, seeking social support, positive reappraisal, and planful problem solving. Other individuals were identified who scored high in both escape-avoidance and distancing. These groups were compared relative to their scores in the adjustment domains. Significant differences were found in two areas, domestic environment and extended family relationships.

It does not seem surprising that persons who seek emotional support, take deliberate actions to improve their situation, and focus on personal growth might report

improved immediate and extended family relationships compared with persons who tended to avoid people and detach themselves from the seriousness of the situation and use wishful thinking to escape the problem.

#### Summary of Chapter

This chapter included results and discussion pertaining to the research questions and their related hypotheses.

The results of this study suggest that there is no difference in the variety and intensity of coping strategies utilized by persons with rheumatoid arthritis and cardiac transplant recipients.

The two medical condition groups do differ in regard to their psychosocial adjustment to illness. Persons with arthritis have greater difficulty than the cardiac transplant recipients in the areas of health-care orientation, extended family relationships, and social environment.

Significant correlations exist between coping strategies and psychosocial adjustment to illness domains. Utilization of confrontive coping is linked with a positive health-care orientation. Distancing as a coping strategy is correlated with poor adjustment in the areas of vocational environment, extended family relationships, and domestic environment.

## CHAPTER 5

### SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

#### Introductory Statement

This chapter will review the purpose, process, and conclusions of this study. Implications of the study and recommendations for future research will be discussed.

#### Study Summary

This study was seen as an opportunity to address some questions regarding how adults with chronic illness cope with the stresses and changes inherent in their physical health situations. The study also measured psychosocial adjustment in seven life domains. An effort was made to assess the link between coping behaviors and psychosocial adjustment.

Two medical diagnostic groups were examined to see if illness-specific coping styles or adjustment domains could be identified.

This researcher believes that with advances in public health standards, nutrition, and medical interventions, more people will survive longer, increasing their likelihood of acquiring some form of chronic health problem. With more and more people experiencing a chronic

illness, it becomes incumbent on health providers to be well prepared to counsel and support individuals to maximize their coping capacity.

This study was accomplished through the voluntary participation of cardiac transplant recipients and persons with rheumatoid arthritis. Questionnaires were mailed to and returned by participants. Four research questions and related hypotheses were studied and tested.

#### Implications

One of the implications of this study is that people use the same strategies to cope with the stress of chronic illness regardless of how the illness manifests itself or the types of medical treatments used.

Another implication is that coping through distancing and escape-avoidance may result in relationship problems and possibly increased psychological and work-related problems. This would suggest that when professionals identify persons who are relying heavily on avoidant coping strategies that an assessment be done to evaluate the outcome of these coping strategies. Possibly it would be appropriate to introduce strategies to expand the coping repertoire of persons who rely heavily on distancing and escape-avoidance.

The study further implies that level of psychosocial adjustment in various life domains may differ by medical

diagnostic group. Because diseases differ in symptom type and severity, disease prognosis, predictability, degree of imposed dependence, and in other ways, different life domains may be affected.

#### Suggestions for Future Research

The results of this study suggest that coping by distancing and through escape-avoidance may contribute to psychosocial problems in some life domains. Cronkite and Moos (1984), in their study of coping, found that active coping was less effective when dealing with problems over which a person has little control. Future research might examine whether different coping mechanisms were selectively effective according to characteristics of the problem. Perceived control may be one such characteristic.

Future research might also consider whether certain coping strategies were more or less effective depending on personality characteristic.

Lazarus and Folkman's (1984) stress model includes the idea of self-concept. Knowing what valued qualities, roles, or goals a person has allows one to predict the circumstances under which a person will feel threatened.

It would be useful to be able to assess for areas of self-concept commitment and to study whether certain coping styles were more useful in dealing with different areas of commitment.



The current study suggests that some coping strategies are potentially more adaptive than others. Future research could examine how coping mechanisms are learned and how one's coping repertoire can be expanded to include additional, less familiar, but hopefully more useful strategies.

Lazarus and Folkman (1984) pointed out that the same stressor may be interpreted as a threat or a challenge. It would be useful to identify factors that contribute to whether an event is processed as harmful and results in fearfulness and anxiety or is processed as a challenge and associated with feelings of excitement and anticipation.

This study only included adult respondents. Because many children also live with a chronic illness, it would be useful to study children's coping patterns and adjustment domains and identify possible strategies for improving productive coping.

This study did not address cultural differences among participants. It would be relevant to know whether there are culture-specific qualities which influence effective coping.

One of the suggestions of this study's results was that coping through distancing and escape-avoidance may contribute to disfunction in certain life domains. It would be interesting to carry out an experimental study in

which persons who rely on escape-avoidance and distancing were taught supplemental coping strategies. One might then measure whether an expanded coping repertoire resulted in changes in psychosocial adjustment.

#### Chapter Summary

This chapter included a summary of the study, implications of the study, and suggestions for future research.

This study gave support to the belief that chronically ill persons use the same coping mechanisms regardless of medical diagnosis. Adjustment domains were found to differ between diagnostic groups. Different health conditions may strain different aspects of a person's social and psychological well being.

The present study gave support to the idea that coping through distancing and escape-avoidance strategies may contribute to problems in some psychosocial adjustment domains.

**APPENDIX A**

**LETTERS FROM SPONSORING PHYSICIANS**


Department of Internal Medicine  
Section of Rheumatology/Allergy & Immunology



Tucson, Arizona 85724  
(602) 626-6041  
FAX 602-626-4884

**MEMORANDUM**

**TO:** Rheumatoid Arthritis Patients

**FROM:** Eric P. Gall, M.D.   
Professor-Internal Medicine (Surgery, FCM)  
Chief-Section of Rheumatology/Allergy & Immunology  
Medical Director, U of A Arthritis Center

**DATE:** April 6, 1990

**RE:** Marla Perry: Project on "Coping and Adjustment in People  
with Rheumatoid Arthritis and Cardiac Transplants Recipients"

I fully support Ms. Perry's study of the above named title. I and my staff appreciate your involvement in this study and look forward to learning from the results.

EPG/cks



**The University of Arizona**

Health Sciences Center  
College of Medicine  
Department of Surgery  
Section of Cardiovascular and  
Thoracic Surgery  
Tucson, Arizona 85724  
(602) 626-6339

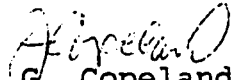
March 27, 1990

Transplant Recipient

RE: Marla Perry, Coping and Adjustment in People with  
Rheumatoid Arthritis and Cardiac Transplant

I fully support Ms. Perry's study of coping and adjustment in people with rheumatoid arthritis and cardiac transplant recipients. We appreciate your involvement in this study and look forward to learning from the results.

Sincerely,

  
Jack G. Copeland, M.D.  
Professor and Chief  
Cardiovascular and Thoracic Surgery

ANM/se

APPENDIX B  
COVER LETTERS,  
WAYS OF COPING QUESTIONNAIRE,  
PSYCHOSOCIAL ADJUSTMENT TO ILLNESS SCALE,  
AND DATA SHEET

Dear Heart Transplant Recipient:

As a nurse who worked for several years with persons experiencing chronic medical illness, I realize that living with an illness can be stressful. As a doctoral student in rehabilitation psychology, I am interested in studying how individuals cope with illness-related stress and what adjustment is achieved in various aspects of life. With improved understanding of healthy coping should come improved skills in assisting persons toward optimal function within the reality of their physical limitations.

The purpose of this study is to examine ways people cope with the stress of chronic illness and how coping strategies relate to adjustment in two groups of people, those with cardiac transplants and those with rheumatoid arthritis. These two conditions were chosen because their related experiences may be different and similar in meaningful ways.

Your participation in this study is being requested. Participation is voluntary and your decision regarding participation will in no way affect your medical treatment. Participation involves completion of a data sheet and two

questionnaires, "Ways of Coping," and "Psychosocial Adjustment of Illness Scale." Your approximate total time is one hour.

Your participation in this project is completely confidential. All questionnaires will be coded with numbers that only I will have access to. They will be kept in a locked file drawer. Your name will not be used in the reporting of the findings, only group information will be discussed.

I appreciate the time you take to complete these forms. Please return the forms in the enclosed pre-paid envelope as soon as they are completed.

Thank you.



Dear Person with Rheumatoid Arthritis:

As a nurse who worked for several years with persons experiencing chronic medical illness, I realize that living with an illness can be stressful. As a doctoral student in rehabilitation psychology, I am interested in studying how individuals cope with illness-related stress and what adjustment is achieved in various aspects of life. With improved understanding of healthy coping should come improved skills in assisting persons toward optimal function within the reality of their physical limitations.

The purpose of this study is to examine ways people cope with the stress of chronic illness and how coping strategies relate to adjustment in two groups of people, those with cardiac transplants and those with rheumatoid arthritis. These two conditions were chosen because their related experiences may be different and similar in meaningful ways.

Your participation in this study is being requested. Participation is voluntary and your decision regarding participation will in no way affect your medical treatment. Participation involves completion of a data sheet and two

questionnaires, "Ways of Coping," and "Psychosocial Adjustment of Illness Scale." Your approximate total time is one hour.

Your participation in this project is completely confidential. All questionnaires will be coded with numbers that only I will have access to. They will be kept in a locked file drawer. Your name will not be used in the reporting of the findings, only group information will be discussed.

I appreciate the time you take to complete these forms. Please return the forms in the enclosed pre-paid envelope as soon as they are completed.

Thank you.

This study is being conducted to explore ways people can cope with the stress of chronic illness and how coping strategies relate to adjustment in two groups of people, those with cardiac transplants and those with rheumatoid arthritis. By signing this form you are agreeing to voluntary participation in this study. You may withdraw this consent at any time.

Non-participation would in no way impact on your medical care and would incur no ill will. All questionnaires will be locked in a file kept by the investigator.

As a participant, you will be asked to complete two questionnaires, "Ways of Coping," and "Psychosocial Adjustment to Illness Scale." Your total time involvement is expected to be approximately one hour. Your responses to the questionnaires will be reviewed by the investigator. In reporting the results of this study, no names will be used and only group data will be discussed. A summary of the study's findings will be shared with you if you so request.

By signing this form you agree to the above stated terms and agree to participate in the study. Thank you for your assistance.

Date \_\_\_\_\_

Signed \_\_\_\_\_

## WAYS OF COPING QUESTIONNAIRE

Instructions

To respond to the statements in this questionnaire, you must have a specific stressful situation in mind. Take a few moments and think about the most stressful situation that you have experienced in the past week.

By "stressful" we mean a situation that was difficult or troubling for you, either because you felt distressed about what happened, or because you had to use considerable effort to deal with the situation. The situation may have involved your family, your job, your friends, or something else important to you. Before responding to the statements, think about the details of this stressful situation, such as where it happened, who was involved, how you acted, and why it was important to you. While you may still be involved in the situation, or it could have already happened, it should be the most stressful situation that you experienced during the week.

As you respond to each of the statements, please keep this stressful situation in mind. Read each statement carefully and indicate with a check mark in the box alongside your answer of to what extent you used it in the situation. Please respond to each item.

1. I just concentrated on what I had to do next--the next step.

a) Does not apply or not used  
 b) Used somewhat  
 c) Used quite a bit  
 d) Used a great deal

2. I tried to analyze the problem in order to understand it better.

a) Does not apply or not used  
 b) Used somewhat  
 c) Used quite a bit  
 d) Used a great deal

3. I turned to work or another activity to take my mind off things.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

4. I felt that time would make a difference--the only thing was to wait.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

5. I bargained or compromised to get something positive from the situation.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

6. I did something that I didn't think would work, but at least I was doing something.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

7. I tried to get the person responsible to change his or her mind.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

8. I talked to someone to find out more about the situation.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

9. I criticized or lectured myself.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

10. I tried not to burn my bridges, but leave things open somewhat.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

11. I hoped for a miracle.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

12. I went along with fate; sometimes I just have bad luck.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

13. I went on as if nothing had happened.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

14. I tried to keep my feelings to myself.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

15. I looked for the silver lining, so to speak; I tried to look on the bright side of things.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

16. I slept more than usual.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

17. I expressed anger to the person(s) who caused the problem.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

18. I accepted sympathy and understanding from someone.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

19. I told myself things that helped me feel better.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

20. I was inspired to do something creative about the problem.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

21. I tried to forget the whole thing.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

22. I got professional help.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

23. I changed or grew as a person.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

24. I waited to see what would happen before doing anything.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

25. I apologized or did something to make up.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

26. I made a plan of action and followed it.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal



27. I accepted the next best thing to what I wanted.
- a) Does not apply or not used
  - b) Used somewhat
  - c) Used quite a bit
  - d) Used a great deal
28. I let my feelings out somehow.
- a) Does not apply or not used
  - b) Used somewhat
  - c) Used quite a bit
  - d) Used a great deal
29. I realized that I had brought the problem on myself.
- a) Does not apply or not used
  - b) Used somewhat
  - c) Used quite a bit
  - d) Used a great deal
30. I came out of the experience better than when I went in.
- a) Does not apply or not used
  - b) Used somewhat
  - c) Used quite a bit
  - d) Used a great deal
31. I talked to someone who could do something concrete about the problem.
- a) Does not apply or not used
  - b) Used somewhat
  - c) Used quite a bit
  - d) Used a great deal
32. I tried to get away from it for a while by resting or taking a vacation.
- a) Does not apply or not used
  - b) Used somewhat
  - c) Used quite a bit
  - d) Used a great deal

33. I tried to make myself feel better by eating, drinking, smoking, using drugs, or medications, etc.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

34. I took a big chance or did something very risky to solve the problem.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

35. I tried not to act too hastily or follow my first hunch.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

36. I found new faith.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

37. I maintained my pride and kept a stiff upper lip.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

38. I rediscovered what is important in life.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

39. I changed something so things would turn out all right.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

40. I generally avoided being with people.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

41. I didn't let it get to me; I refused to think too much about it.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

42. I asked advice from a relative or friend I respected.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

43. I kept others from knowing how bad things were.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

44. I talked to someone about how I was feeling.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

45. I talked to someone about how I was feeling.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

46. I stood my ground and fought for what I wanted.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

47. I took it out on other people.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

48. I drew on my past experiences; I was in a similar situation before.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

49. I knew what had to be done, so I doubled my efforts to make things work.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

50. I refused to believe that it had happened.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

51. I promised myself that things would be different next time.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

52. I came up with a couple of different solutions to the problem.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

53. I accepted the situation, since nothing could be done.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

54. I tried to keep my feelings about the problem from interfering with other things.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

55. I wished that I could change what had happened or how I felt.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

56. I changed something about myself.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

57. I daydreamed or imagined a better time or place than the one I was in.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

58. I wished that the situation would go away or somehow be over with.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

59. I had fantasies or wishes about how things might turn out.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

60. I prayed

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

61. I prepared myself for the worst.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

62. I went over in my mind what I would say or do.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

63. I thought about how a person I admire would handle this situation and used that as a model.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

64. I tried to see things from the other person's point of view.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

65. I reminded myself how much worse things could be.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

66. I jogged or exercised.

- a) Does not apply or not used
- b) Used somewhat
- c) Used quite a bit
- d) Used a great deal

## PSYCHOSOCIAL ADJUSTMENT TO ILLNESS SCALE

INSTRUCTIONS

The present form contains a set of questions concerning the effects that your health condition has had on you. We are interested in knowing what effects it has had on your relationships and performance at home and on your job, as well as on family and personal relationships. Other questions deal with its effects on your social and leisure time activities, and how you have felt emotionally.

In answering each question, please put a check mark in the box alongside the answer that best describes your experience. Please answer all the questions and try not to skip any. If none of the answers to a question match your experience exactly;, please choose the answer that comes closest to the experience you have had.

The time we would like you to refer to is the past 30 days, including today. Answer each question in terms of what your experience has been like during this time.

Some questions on the form assume that you are married or have a steady partner you are close to. Other questions ask about family relationships. If these questions do not apply; to you because you are unmarried, or you have no family or partner, please leave them blank. Try to answer all the questions that do apply; to you, however.

Section II asks questions about your job performance. If you have either full-time or substantial part-time employment, please answer int terms of your job. If you are primarily a student, answer in terms of your school work. If you are a housewife, answer as though housework, neighbors, etc. are your work environment.

Thank you.



## PSYCHOSOCIAL ADJUSTMENT TO ILLNESS SCALE

1. Which of the following statements best describes your usual attitude about taking care of your health?
  - a) I am very concerned and pay close attention to my personal health.
  - b) Most of the time I pay attention to my health care needs.
  - c) Usually, I try to take care of health matters but sometimes I just don't get around to it.
  - d) Health care is something that I just don't worry too much about.
  
2. Your present physical health status probably requires some special attention and care on your part. Would you please select the statement below that best describes your reaction?
  - a) I do things pretty much the way I always have done them and I don't worry or take any special considerations for my health condition.
  - b) I try to do all the things I am supposed to do to take care of myself, but lots of times I forget or I am too tired or busy.
  - c) I do a pretty good job taking care of my present health condition.
  - d) I pay close attention to all the needs of my present health condition and do everything I can to take care of myself.
  
3. In general, how do you feel about the quality of medical care available today and the doctors who provide it?
  - a) Medical care has never been better and the doctors who give it are doing an excellent job.
  - b) The quality of medical care available is very good but there are some areas that could stand improvement.
  - c) Medical care and doctors are just not of the same quality they once were.
  - d) I don't have much faith in doctors or medical care today.

4. During your present medical condition you have received treatment from both doctors and medical staff. How do you feel about them and the treatment you have received from them?
- a) I am very unhappy with the treatment I have received and don't think the staff has done all they could have for me.
  - b) I have not been impressed with the treatment I have received, but I think it is probably the best they can do.
  - c) The treatment has been pretty good on the whole, although there have been a few problems.
  - d) The treatment and the treatment staff have been excellent.
5. When they are ill, different people expect different things about their illness, and have different attitudes about being ill. Could you please check the statement below which comes closest to describing your feelings.
- a) I am sure that I am going to overcome the health condition and its problems quickly and get back to being my old self.
  - b) My health condition has caused some problems for me, but I feel I will overcome them fairly soon, and get back to the way I was before.
  - c) My health condition has really put a great strain on me, both physically and mentally, but I am trying very hard to overcome it, and feel sure that I will be back to my old self one of these days.
  - d) I feel worn out and very weak from my health condition and there are times when I don't know if I am really ever going to be able to overcome it.

6. Being ill can be a confusing experience, and some patients feel that they do not receive enough information and detail from their doctors and the medical staff about their health status. Please select a statement below which best describes your feelings about this matter.
- a) My doctor and the medical staff have told me very little about my health status even though I have asked more than once.
  - b) I do have some information about my health status but I feel I would like to know more.
  - c) I have a pretty fair understanding about my health status and feel that if I want to know more I can always get the information.
  - d) I have been given a very complete picture of my health status and my doctor and the medical staff have given me all the details I wish to have.
7. In a health condition such as yours, people have different ideas about their care and what to expect from it. Please select one of the statements below which best describes what you expect about your health care.
- a) I believe my doctors and medical staff are quite able to direct my care and feel it is the best treatment I could receive.
  - b) I have trust in my doctor's direction of my health care; however, sometimes I have doubts about it.
  - c) I don't like certain parts of my health care which are very unpleasant, but my doctors tell me I should go through it anyway.
  - d) In many ways I think my health care is worse than the illness, and I am not sure it is worth going through it.

8. In a medical condition such as yours, patients are given different amounts of information about their treatment. Please select a statement from those below which best describes information you have been given about your treatment.
- a) I have been told almost nothing about my treatment and feel left out about it.
  - b) I have some information about my treatment but not as much as I would like to have.
  - c) My information concerning treatment is very complete, but there are one or two things I still want to know.
  - d) I feel my information concerning treatment is very complete and up-to-date.

## Section II

1. Has your health status interfered with your ability to do your job (schoolwork)?
- a) No problems with my job
  - b) Some problems, but only minor ones
  - c) Some serious problems
  - d) Medical condition has totally prevented me from doing my job
2. How well do you physically perform your job (studies) now?
- a) Poorly
  - b) Not too well
  - c) Adequately
  - d) Very well
3. During the past 30 days, have you lost any time at work (school) due to your health status?
- a) 3 days or less
  - b) 1 week
  - c) 2 weeks
  - d) More than 2 weeks
4. Is your job (school) as important to you now as it was before your medical condition?
- a) Little or no importance to me now
  - b) A lot less important

- c) Slightly less important
  - d) Equal or greater importance than before
5. Have you had to change your goals concerning your job (education) as a result of your health problems?
- a) My goals are unchanged
  - b) There has been a slight change in my goals
  - c) My goals have changed quite a bit
  - d) I have changed my goals completely
6. Have you noticed any increase in problems with your co-workers (students, neighbors) since your illness?
- a) A great increase in problems
  - b) A moderate increase in problems
  - c) A slight increase in problems
  - d) None

### Section III

1. How should you describe your relationship with your husband or wife (partner, if not married) since your health problems?
- a) Good
  - b) Fair
  - c) Poor
  - d) Very poor
2. How would you describe your general relationships with the other people you live with (e.g., children, parents, aunts, etc.)?
- a) Very poor
  - b) Poor
  - c) Fair
  - d) Good
3. How much has your health condition interfered with your work and duties around the house?
- a) Not at all
  - b) Slight problems, easily overcome
  - c) Moderate problems, not all of which can be overcome
  - d) Severe difficulties with household duties

4. In those areas where your health status has caused problems with your household work, how has the family shifted duties to help you out?
- a) The family has not been able to help out at all
  - b) The family has tried to help but many things are left undone
  - c) The family has done well except for a few minor things
  - d) No problems
5. Has your health condition resulted in a decrease in communication between you and members of your family?
- a) No decrease in communication
  - b) A slight decrease in communication
  - c) Communication has decreased, and I feel somewhat withdrawn from them.
  - d) Communication has decreased a lot, and I feel very alone
6. Some people with a condition like yours feel they need help from other people (friends, neighbors, family, etc.) to get things done from day-to-day. Do you feel you need such help and is there anyone to provide it?
- a) I really need help but seldom is anyone around to help
  - b) I get some help, but I can't count on it all the time
  - c) I don't get all the help I need all of the time, but most of the time help is there when I need it
  - d) I don't feel I need such help, or the help I need is available from my family or friends
7. Have you experienced any physical disability with your health condition?
- a) No physical disability
  - b) A slight physical disability
  - c) A moderate physical disability
  - d) A severe physical disability

8. A condition such as yours can sometimes cause a drain on the family finances; are you having any difficulties meeting the financial demands of your health condition?
- a) Severe financial hardships
  - b) Moderate financial problems
  - c) A slight financial drain
  - d) No money problems

#### Section IV

1. Sometimes having a health condition can cause problems in a relationship. Has your health status led to any problems with your husband or wife (partner, if not married)?
- a) There has been no change in our relationship
  - b) We are a little less close since my condition
  - c) We are definitely less close since my condition
  - d) We have had serious problems or a break in our relationship since my condition
2. Sometimes when people are ill they report a loss of interest in sexual activities. Have you experienced less sexual interest since your condition?
- a) Absolutely no sexual interest since condition
  - b) A marked loss of sexual interest
  - c) A slight loss of sexual interest
  - d) No loss in sexual interest
3. Physical health problems sometimes cause a decrease in sexual activity. Have you experienced any decrease in the frequency of your sexual activities?
- a) No decrease in sexual activities
  - b) Slight decrease in sexual activities
  - c) Marked decrease in sexual activities
  - d) Sexual activities have stopped
4. Has there been any change in the pleasure or satisfaction you normally experience from sex?
- a) Sexual pleasure and satisfaction have stopped
  - b) A marked loss of sexual pleasure or satisfaction
  - c) A slight loss of sexual pleasure or satisfaction
  - d) No change in sexual satisfaction

5. Sometimes a health condition will cause an interference in a person's ability to perform sexual activities even though they are still interested in sex. Has this happened to you, and if so, to what degree.
- a) No change in my ability to have sex
  - b) Slight problems with my sexual performance
  - c) Constant sexual performance problems
  - d) Totally unable to perform sexually
6. Sometimes a health condition will interfere with a couples' normal sexual relationship and cause arguments or problems between them. Have you and your partner had any arguments like this, and if so, to what degree?
- a) Constant arguments
  - b) Frequent arguments
  - c) Some arguments
  - d) No arguments

#### Section V

1. Have you had as much contact as usual (either personally or by telephone) with members of your family outside your household since your condition?
- a) Contact is the same or greater since condition
  - b) Contact is slightly less
  - c) Contact is markedly less
  - d) No contact since illness
2. Have you remained as interested in getting together with these members of your family since your condition?
- a) Little or no interest in getting together with them
  - b) Interest is a lot less than before
  - c) Interest is slightly less
  - d) Interest is the same or greater since condition



3. Sometimes, when people have a health condition, they are forced to depend on members of the family outside their household for physical help. Do you need physical help from them, and do they supply the help you need?
- a) I need no help, or they give me all the help I need
  - b) Their help is enough, except for some minor things
  - c) They give me some help but not enough
  - d) They give me a little or no help even though I need a great deal
4. Some people socialize a great deal with members of their family outside their immediate household. Do you do much socializing with these family members, and has your health status reduced such socializing?
- a) Socializing with them has been pretty much eliminated.
  - b) Socializing with them has been reduced significantly
  - c) Socializing with them has been reduced somewhat
  - d) Little or no socializing, or slight or no effect of health condition
5. In general, how have you been getting along with these members of your family recently?
- a) Good
  - b) Fair
  - c) Poor
  - d) Very poor

#### Section VI

1. Are you still as interested in your leisure time activities and hobbies as you were prior to your health problems?
- a) Same level of interest as previously
  - b) Slightly less interest than before
  - c) Significantly less interest than before
  - d) Little or no interest remaining

2. How about actual participation? Are you still actively involved in doing those activities?
- a) Little or no participation at present
  - b) Participation reduced significantly
  - c) Participation reduced slightly
  - d) Participation remains unchanged
3. Are you as interested in leisure time activities with your family (i.e., playing cards and games, taking trips, going swimming, etc.) as you were prior to your health problems?
- a) Same level of interest as previously
  - b) Slightly less interest than before
  - c) Significantly less interest than before
  - d) Little or no interest remaining
4. Do you still participate in those activities to the same degree you once did?
- a) Little or no participation at present
  - b) Participation reduced significantly
  - c) Participation reduced slightly
  - d) Participation remains unchanged
5. Have you maintained your interest in social activities since your health condition (e.g., social clubs, church groups, going to the movies, etc.)?
- a) Same level of interest as previously
  - b) Slightly less interest than before
  - c) Significantly less interest than before
  - d) Little or no interest remaining
6. How about participation? Do you still go out with your friends and do those things?
- a) Little or no participation at present
  - b) Participation reduced significantly
  - c) Participation reduced slightly
  - d) Participation remains unchanged

## Section VII

1. Recently, have you felt afraid, tense, nervous, or anxious?  
 a) Not at all  
 b) A little bit  
 c) Quite a bit  
 d) Extremely
2. Recently, have you felt sad, depressed, lost interest in things, or felt hopeless?  
 a) Extremely  
 b) Quite a bit  
 c) A little bit  
 d) Not at all
3. Recently, have you felt angry, irritable, or had difficulty controlling your temper?  
 a) Not at all  
 b) A little bit  
 c) Quite a bit  
 d) Extremely
4. Recently, have you blamed yourself for things, felt guilty, or felt like you have let people down?  
 a) Extremely  
 b) Quite a bit  
 c) A little bit  
 d) Not at all
5. Recently, have you worried much about your health status?  
 a) Not at all  
 b) A little bit  
 c) Quite a bit  
 d) Extremely
6. Recently, have you been feeling down on yourself or less valuable as a person?  
 a) Extremely  
 b) Quite a bit

- c) A little bit
- d) Not at all

7. Recently, have you been concerned that your health condition has caused changes in the way you look that make you less attractive?

- a) Not at all
- b) A little bit
- c) Quite a bit
- d) Extremely

## Data Sheet

Name: \_\_\_\_\_

Male \_\_\_\_\_ Female \_\_\_\_\_

Date of birth \_\_\_\_\_

Medical Condition: Cardiac transplant \_\_\_\_\_

Rheumatoid arthritis \_\_\_\_\_

Time since: Diagnosis of cardiac illness \_\_\_\_\_  
(Approximate years and months)Diagnosis of rheumatoid  
arthritis \_\_\_\_\_  
(Approximate years and months)

Frequency of symptoms and/or medication side effects:

1. Almost constant \_\_\_\_\_
2. 2-3 times per day \_\_\_\_\_
3. 1 time per day \_\_\_\_\_
4. 2-3 times per week \_\_\_\_\_
5. 1 time per week \_\_\_\_\_
6. 2-3 times per month \_\_\_\_\_
7. 1 time per month \_\_\_\_\_
8. Seldom  
(Describe frequency or pattern) \_\_\_\_\_

How stressful is it for you to experience symptoms and/or medication side effects?

1. extremely stressful \_\_\_\_\_
2. very stressful \_\_\_\_\_

3. quite stressful \_\_\_\_\_
4. moderately stressful \_\_\_\_\_
5. somewhat stressful \_\_\_\_\_
6. a little stressful \_\_\_\_\_
7. slightly stressful \_\_\_\_\_
8. not at all stressful \_\_\_\_\_

How much personal control do you believe you have over your daily symptoms and/or medication side effects?

1. absolutely no control \_\_\_\_\_
2. slight control \_\_\_\_\_
3. a little control \_\_\_\_\_
4. some control \_\_\_\_\_
5. moderate control \_\_\_\_\_
6. substantial control \_\_\_\_\_
7. a large amount of control \_\_\_\_\_
8. an extreme amount of control \_\_\_\_\_

How much personal control do you believe you have of the long-term course of your physical health?

1. absolutely no control \_\_\_\_\_
2. slight control \_\_\_\_\_
3. a little control \_\_\_\_\_
4. some control \_\_\_\_\_
5. moderate control \_\_\_\_\_
6. substantial control \_\_\_\_\_

7. a large amount of control \_\_\_\_\_

8. an extreme amount of  
control \_\_\_\_\_





## REFERENCES

- Affleck, G., Tennen, H., Pfeiffer, C., & Fifield, J. (1987). Appraisals of control and predictability in adapting to a chronic disease. Journal of Personality and Social Psychology, 53, 273-279.
- Allender, J., Shisslak, C., Kaszniak, A., & Copeland, J. (1983). Stages of psychological adjustment associated with heart transplantation. Heart Transplantation, 2, 228-231.
- Anderson, K. O., Bradley, L. A., Young, L. D., McDaniel, L. K., & Wise, C. M. (1985). Rheumatoid arthritis: Review of psychological factors related to etiology, effects, and treatment. Psychological Bulletin, 98, 358-387.
- Christopherson, L. K. (1982). Heart transplants, The Hasting Center report. 18-21.
- Coelho, G., Hamburg, D., & Adams, J. (1974). Coping and adaptation. New York: Basic Books.
- Cohen, S., & Wills, T. (1985). Stress, social support, and the buffering hypothesis. Psychological Bulletin, 98, 310-357.
- Counte, M. A., Beiliauskas, L. A., & Pavlou, M. (1983). Stress and personal attitudes in chronic illness. Archives of Physical Illness, 64, 272-275.

- Coyne, J. C., & Lazarus, R. S. (1980). Cognitive style, stress perception, and coping. In I. L. Kutash & L. B. Schlesinger & Associates (Eds.), Handbook on stress and anxiety. San Francisco: Jossey-Bass.
- Craig, H. M., & Edwards, J. E. (1983). Adaptation to chronic illness: An eclectic model for nurses. Journal of Advanced Nursing, 8, 397-404.
- Cromwell, R. L., Butterfield, E. C., Brayfield, F. M., & Cuerry, J. J. (1977). Acute myocardial infarction. St. Louis: Mosby.
- Cronkite, R. C., & Moos, R. H. (1984). The role of predisposing and moderating factors in the stress-illness relationship. Journal of Health and Social Behavior, 25, 372-393.
- Darby, P. L., & Schmidt, P. J. (1988). Psychiatric consultation in rheumatology: A review of 100 cases. Canadian Journal of Psychiatry, 33, 290-293
- Dell Orto, A. (1984). Coping with the enormity of illness and disability. Rehabilitation Literature, 45, 22-23.
- Dembo, T., Leviton, C. L., & Wright, B. A. (1956). Adjustment to misfortune: A problem of social psychological rehabilitation. Artificial Limbs, 3, 4-62.

- De-Nour, A. K. (1982). Psychosocial Adjustment to Illness Scale (PAIS): A study of chronic hemodialysis patients. Journal of Psychosomatic Research, 26, 11-22.
- Derogatis, L. R. (1986). The Psychosocial Adjustment to Illness Scale (PAIS). Journal of Psychosomatic Research, 30, 77-91.
- Derogatis, L. R., Abeloff, M. D., & Melisaratos, N. (1979). Psychological coping mechanisms and survival time in metastatic breast cancer. Journal of the American Medical Association, 242, 1504-1508.
- Derogatis, L. R., & Lopez, M. C. (1983). The psychosocial adjustment to illness scale: Administration, scoring and procedures manual. Baltimore: Clinical Psychometric Research, Johns Hopkins University School of Medicine.
- Dimsdale, J. E. (1976). The coping behaviors of Nazi concentration camp survivors. In R. H. Moos (Ed.), Human adaptation: Coping with life crises. Lexington, MA: D. C. Heath.
- Duthie, J. J. R., Brown, P. E., Truelove, L. H., Baragar, F. D., & Lawrie, A. J. (1964). Course and prognosis in rheumatoid arthritis. Annals of the Rheumatic Diseases, 23, 193-204.

- Emery, R. W., & Copeland, J. G. (1985). Heart transplantation in Arizona. Heart Transplantation, 4, 203-205.
- Feldman, D. J. (1974). Chronic disabling illness: A holistic view. Journal of Chronic Diseases, 27, 287-291.
- Felton, B. J., & Revenson, T. A. (1984). Coping with chronic illness: A study of illness controllability and the influence of coping strategies on psychological adjustment. Journal of Consulting and Clinical Psychology, 52, 343-353.
- Felton, B. J., Revenson, T. A., & Hinricksen, G. A. (1984). Stress and coping in the explanation of psychological adjustment among chronically ill adults. Social Science and Medicine, 18, 889-898.
- Folkman, S. (1984). Personal control and stress and coping processes: A theoretical analysis. Journal of Personality and Social Psychology, 46, 839-852.
- Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. Journal of Health and Social Behavior, 21, 219-239.
- Folkman, S., & Lazarus, R. S. (1988). Manual for the ways of coping questionnaire. Palo Alto, CA: Consulting Psychologists Press.

- Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. (1986). The dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. Journal of Personality and Social Psychology, 51, 992-1003.
- Forsyth, G., Delaney, K., & Gresham, M. (1984). Vying for a winning position: Management style of the chronically ill. Research in Nursing and Health, 7, 181-188.
- Frye, B. A. (1986). A model of wellness seeking behavior in traumatic spinal cord injured victims. Rehabilitation Nursing, 11, 6, 7, 14.
- Griepp, R. B., & Ergin, M. A. (1984). The history of experimental heart transplantation. Heart Transplantation, 3, 145-151.
- Gulick, E. E. (1986). The self-assessment of health among the chronically ill. Topics in Clinical Nursing, 8, 74-82.
- Halliday, J. L. (1941). The concept of psychosomatic rheumatism. Annals of Internal Medicine, 15, 666-673.
- Harris, E. D. (1981). Rheumatoid arthritis: The clinical spectrum. In W. N. Kelley, E. D. Harris, S. Ruddy, & C. B. Sledge (Eds.), Textbooks of Rheumatology (pp. 928-963). Philadelphia: Saunders.

- Harvison, A., Jones, B. M., McBride, M., Taylor, F., Wright, O., & Chang, V. P. (1988). Rehabilitation after heart transplantation: The Australian experience. Journal of Heart Transplantation, 7, 337-341.
- Hawley, D. J., & Wolfe, F. (1988). Anxiety and depression in patients with rheumatoid arthritis: A prospective study of 400 patients. The Journal of Rheumatology, 15, 932-941.
- Holmes, T. H., & Masuda, M. (1974). Life changes and illness susceptibility. In B. S. Dohrenwend & B. P. Dohrenwend (Eds.), Stressful life events: Their nature and effects. New York: Wiley.
- Holmes, T. H., & Rahe, R. H. (1967). The social adjustment rating scale. Journal of Psychosomatic Research, 11, 213-218.
- Holroyde, K. A., & Lazarus, R. (1982). Stress, coping and somatic adaptation. In L. Goldberg & S. Breznitz (Eds.), Handbook of stress: Theoretical and clinical aspects. New York: Free Press.
- Janoff-Bulman, R., & Brickman, P. (1980). Expectations and what people learn from failure. In N. T. Feather (Ed.), Expectancy, incentive, and action. Hillsdale, NJ: Earlbaum.

- Johnson, A., Shapiro, L., & Alexander, F. (1947). Preliminary report on a psychosomatic study of rheumatoid arthritis. Psychosomatic Medicine, 9, 295-302.
- Kaplan-De Nour, A. (1982). Psychosocial adjustment to illness scale (PAIS): A study of chronic hemodialysis patients. Journal of Psychosomatic Research, 26, 11-26.
- King, K. B. (1985). Measurement of coping strategies, concerns, and emotional response in patients undergoing coronary artery bypass grafting. Heart and Lung, 14, 579-586.
- Kobasa, S. C. (1982). The hardy personality: Toward a social psychology of stress and health. In J. Suls (Ed.), Social psychology of health and illness. Hillsdale, NJ: Erlbaum.
- Korner, I. N. (1970). Hope as a method of coping. Journal of Consulting and Clinical Psychology, 34, 134-139.
- Lazarus, R. S., De Longis, A., Folkman, S., & Gruen, R. (1985). Stress and adaptation outcomes: The problems of confounded measures. American Psychologist, 40, 779.
- Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal and coping. New York: Springer.
- Levine, S., & Ursin, H. (Eds.), Coping and health. New York: Plenum.

- Lewis, K. (1983). Grief in chronic illness and disability. Journal of Rehabilitation, 49, 8-11.
- Lough, M. E., Lindsey, A. M., Shinn, J. A., & Stotts, N. A. (1987). Impact of symptom frequency and symptom distress on self-reported quality of life in heart transplant recipients. Heart and Lung, 16, 193-200.
- Lowery, B., & Jacobsen, B. (1985). Attributional analysis of chronic illness outcomes. Nursing Research, 34, 82-88.
- Masi, A. T., & Meetsger, T. A. (1979). Epidemiology of the rheumatic diseases. In D. J. McCarty, Jr. (Ed.), Arthritis and allied conditions (9th ed., pp. 11-30). Philadelphia: Lea & Febiger.
- Mattson, A. (1979). Long-term physical illness in childhood: A challenge to psychosocial adaptation. In C. A. Garfield (Ed.), Stress and survival. St. Louis: C. V. Mosby.
- McAleer, M. J., Copeland, J., Fuller, J., & Copeland, J. G. (1985). Psychological aspects of heart transplantation. Heart Transplantation, 4, 232-233.
- McCrae, R. R. (1984). Situational determinants of coping responses: Loss, threat, and challenge. Journal of Personality and Social Psychology, 46, 919-928.



- McFarlane, A. C., & Brooks, P. M. (1988). An analysis of the relationship between psychological morbidity and disease activity in rheumatoid arthritis. The Journal of Rheumatology, 15, 926-931.
- McFarlane, A. H., Norman, G. R., Streiner, D. L., & Roy, R. C. (1983). The process of social stress. Journal of Health and Social Behavior, 24, 160-173.
- Miller, J. F. (1983). Coping with chronic illness: Overcoming powerlessness. Philadelphia: F. A. Davis.
- Miller, J. F. (1985). Assessment of loneliness and spiritual well-being in chronically ill and healthy adults. Journal of Professional Nursing, 1, 79-85.
- Moos, R. H. (Ed.). (1976). Human adaptation: Coping with life crises. Lexington, MA: D. C. Heath.
- Moos, R. H. (Ed.). (1986). Coping with life crises: An integrated approach. New York: Plenum.
- Moos, R. H., & Soloman, G. F. (1964). Minnesota Multiphasic Personality Inventory response patterns with rheumatoid arthritis. Journal of Psychosomatic Research, 8, 17-21.
- Morrow, G. R., Chiarello, R. J., & Derogatis, L. R. (1978). A new scale for assessing patient's psychosocial adjustment to medical illness. Psychological Medicine, 8, 605-610.

- Mueller, D. P., Edwards, D. W., Yarvis, R. M. (1977).  
Stressful life events and psychiatric symptomatology:  
Change or undesirability. Journal of Health and Social  
Behavior, 18, 307-316.
- Noble, D. N., & Hamilton, A. K. (1983, November/December).  
Coping and complying: A challenge in health care.  
Social Work, 462-466.
- Payne, R. (1985). In J. V. Mitchell (Ed.), The ninth  
mental measurements yearbook, (Vol. 2). Lincoln:  
University of Nebraska Press.
- Pearlin, L. I., Lieberman, M. A., Mengalghan, E. G., &  
Mullan, J. T. (1981). The stress process. Journal of  
Health and Social Behavior, 22, 337-356.
- Pearlin, L. I., & Schooler, C. (1978). The structure of  
coping. Journal of Health and Social Behavior, 19,  
2-21.
- Pereira, B. (1984). Loss and grief in chronic illness.  
Rehabilitation Nursing, 9, 20-22.
- Pollock, S. E. (1986). Human responses to chronic illness:  
Physiologic and psychosocial adaptation. Nursing  
Research, 35, 90-95.
- Prior, P., Symmons, D. P. M., Scott, D. L., Brown, R., &  
Hawkins, C. F. (1984). Cause of death in rheumatoid  
arthritis. British Journal of Rheumatology, 23, 92-99.

- Riggs, G. K., & Gall, E. P. (Eds.). (1984). Rheumatic diseases: Rehabilitation and management. Boston: Butterworth.
- Robbins, P. R., & Tancke, R. H. (1978). A factor analysis of coping behaviors. Journal of Clinical Psychology, 34, 379-380.
- Schulz, R., & Decker, S. (1985). Long-term adjustment to physical disability: The role of social support, perceived control, and self blame. Journal of Personality and Social Psychology, 48, 1162-1172.
- Schumacher, H. R. (1975). Synovial membrane and fluid morphologic alterations in early rheumatoid arthritis: Microvascular injury and virus-like particles. Annals of the New York Academy of Sciences, 256, 39-64.
- Seeman, M., & Seeman, T. E. (1983). Health behavior and personal autonomy: A longitudinal study of the sense of control in illness. Journal of Health and Social Behavior, 24, 144-160.
- Sexton, D. L., & Munro, B. H. (1985). Impact of a husband's chronic illness (COPD) on the spouse's life. Research in Nursing and Health, 8, 83-90.
- Sidle, A., Moss, R., Adams, J., & Cody, P. (1969). Development of a coping scale. Archives of General Psychiatry, 20, 226-232.

- Solis, E., & Kaye, M. P. (1986). The Registry of the International Society for Heart Transplantation: Third official report-June 1986. The Journal of Heart Transplantation, 5, 2-5.
- Spergel, P., Ehrlich, G. E., & Glass, D. (1978). The rheumatoid arthritic personality: A psycho diagnostic myth. Psychosomatics, 19, 79-86.
- Stanhope, M., & Lancaster, J. (1988). Community health nursing. St. Louis: C. V. Mosby.
- Stewart, A. J. (1978). A longitudinal study of coping styles in self-defining and socially defined women. Journal of Consulting and Clinical Psychology, 46, 1079-1084.
- Stewart, T., & Shields, C. (1985). Grief in chronic illness: Assessment and management. Archives of Physical Medicine and Rehabilitation, 66, 447-450.
- Stone, A. A., & Neale, J. M. (1984). New measure of daily coping: Development and preliminary results. Journal of Personality and Social Psychology, 46, 892-906.
- Stone, C., Cohen, F., & Adler, N. E. (1979). Health psychology: A handbook. San Francisco: Jossey-Bass.
- Suszycchi, L. H. (1986). Social work groups on a heart transplant program. Journal of Heart Transplantation, 5, 166-170.

- Watts, D., Freeman, A. M., McGiffin, D. G., Kirklin, J. K., McVay, R., & Karp, R. B. (1984). Psychiatric aspects of cardiac transplantation. Heart Transplantation, 3, 243-247.
- Weiner, H. (1977). Psychobiology and human disease. New York: Elsevier.
- Weisman, A. D., & Sobel, H. J. (1979). Coping with cancer a thorough self-instruction: A hypothesis. Journal of Human Stress, 5, 3-8.
- Weisman, A. D., & Worden, J. W. (1976-77). The existential plight in cancer: Significance of the first 100 days. International Journal of Psychiatry in Medicine, 7, 1-15.
- Wheaton, B. (1983). Stress, personal coping resources, and psychiatric symptoms: An investigation of interactive models. Journal of Health and Social Behavior, 24, 208-229.
- White, R. W. (1976). Strategies of adaptation. In R. H. Moos (Ed.), Human adaptation: Coping with life crises. Lexington, MA: D. C. Heath.
- Wright, B. A. (1960). Physical disability: A psychological approach. New York: Harper & Row.
- Wright, G. N. (1980). Total rehabilitation. Boston: Little, Brown.

Wyler, A. R., Masuda, M., & Holmes, T. H. (1971).

Magnitude of life events and seriousness of illness.

Psychosomatic Medicine, 33, 115-122.

Zuaifler, N. J. (1983). Pathogenesis of the joint disease of rheumatoid arthritis. American Journal of Medicine, 755, 3-8.