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Coping mechanisms reported by cardiac transplant patients in acute rejection

White-Williams, Connie, M.S.N.

University of Alabama at Birmingham, 1991



COPING MECHANISMS REPORTED BY CARDIAC TRANSPLANT PATIENTS IN ACUTE REJECTION

by

CONNIE WHITE-WILLIAMS

A THESIS

Submitted in partial fulfillment of the requirements for the degree of Master of Science in Nursing in the School of Nursing, The University of Alabama at Birmingham

BIRMINGHAM, ALABAMA

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Connie White-Williams

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ABSTRACT

Coping is a common process experienced by those who have difficultly handling the stress of a particular situation and must then draw on something else. Lazarus and Folkman (1984) define coping as constantly changing cognitive and behavioral efforts to manage specific internal or external demands that are exceeding the resources of the person. While coping has been described in many different patient and community populations, there is no reported description of the coping mechanisms of cardiac transplant patients. Therefore, the purpose of the present study was to describe the coping mechanisms reported by heart transplant patients during a rejection episode. The sample consisted of six adult heart transplant patients who were admitted to the hospital with the diagnosis of acute rejection.

Data were collected via structured interviews and cassette tape recordings. Interviews were conducted within 48 hours of admission. After the interview, the Jalowiec Coping Scale (JCS) was administered. Case presentations of the subjects' medical history and hospital course were presented, as well as responses to the interviews, which were transcribed from recorded transcripts. Results from the JCS were also reported.

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Findings revealed that five of the six subjects reported that they coped with rejection. All subjects identified being admitted to the hospital as the worst part of rejection. As identified from the JCS, the most frequently used coping mechanisms were prayer and hope; the least frequently used coping methods were blaming others and drinking. It was recommended that health care professionals be aware of these findings, that the study be replicated with a larger sample, and that it would be useful to identify stressors associated with this situation.

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CHAPTER I

Introduction

Cardiac transplantation is a widely accepted treatment for end-stage heart disease. The International Health Transplant Registry has reported that more than 12,600 cardiac transplant operations have been performed since 1980 (Kriett & Kaye, 1990). In addition, the long-term success of cardiac transplantation has been documented in 236 transplant centers worldwide. Overall, actual survival at 1 year is 81% and at 5 years is 72% (Kriett & Kaye).

Rejection of the transplanted heart is a major cause of death after heart transplantation. Followed by operative technical complications, rejection accounts for approximately 18% of early deaths (Kriett & Kaye, 1990). More than 70% of late deaths are caused by either rejection or infection (Kriett & Kaye). Rejection is most common during the first 8 weeks after surgery and is less problematic after 2 years (Kirklin, Naftel, Kirklin, & Blackstone, 1988). Diagnosis of rejection is made conclusively by performing a right ventricular endomyocardial biopsy. This procedure is scheduled on a routine basis according to a center's protocol; however, many biopsies are performed because of the patient's symptoms. Signs and symptoms of rejection may include fever, dyspnea, decreased exercise tolerance,

hypotension, fatigue, or a vague feeling of not feeling well. Treatment of rejection depends on its severity. One method of determining the severity of rejection is a histological scale which classifies rejection as mild, moderate, severe, or resolving (Billingham, 1979). At most centers, mild rejection is not treated; however, moderate and severe rejection requires medical management. Initially, rejection is usually treated with Methylprenisolone or oral Prednisone. If rejection persists, more potent immunosuppressive drugs may be administered to reverse the immune response. Most rejection episodes require the patient to be hospitalized for a period of time.

Rejection, as defined in <u>New Websters Dictionary of the</u> <u>English Language</u> (1975), means to be refused, declined harshly, or thrown away as useless. This more emotional definition is quite synonymous with the medical definition of rejection in that the transplanted heart is being refused and thus, is rejecting the patient. Nursing and medical lit-erature have unlimited published reports on the medical diagnosis and treatment of rejection; however, there are few published papers on how the patient feels emotionally or copes with rejection.

Transplant patients are faced with the possibility of rejection every day of their lives. Patients must be aware of the signs and symptoms and alert the transplant team if any development of symptoms occur. This awareness brings feelings of ambivalence for the patient since most patients

realize that signs of rejection lead to a biopsy for diagnosis and possible hospitalization.

Allender, Shisslak, Kaszniak, and Copeland (1983) state that when a rejection episode occurs, transplant patients realize that they are still sick. Transplant patients believe that they have traded symptoms of their former illness for symptoms of cardiac transplantation. Therefore, symptoms of chest pain, fatigue, and dyspnea due to low cardiac output are replaced by new problems of rejection and infection. As the rejection resolves, the possible depression or despondency that is associated with rejection improves also (Allender et al.).

Misiazek, Novak, and Potter (1984) have found that most of the despair and ambivalence experienced by transplant patients is due to the symptoms and feelings related to rejection. Misiazek et al. have reported that transplant patients reacted to rejection with a sense of finality. Furthermore, alerting and teaching the patients about rejection did not seem to minimize the emotional impact of the event once it occurred (Misiazek et al.). Both Allender et al. (1983) and Misiaszek et al. describe the feelings patients experience during rejection, but they did not examine how the patients coped with the rejection event.

With no previously documented reports in the nursing or medical literature on how cardiac transplant patients cope during a rejection episode, research is necessary to describe the coping mechanisms utilized by patients in rejection. This information would aid health care professionals, especially nurses in the field of transplantation, to understand the coping strategies of patients in rejection and could have an impact on nursing and medical interventions related to the management of cardiac transplant patients.

Statement of the Purpose

The purpose of this study was to describe the coping mechanisms utilized during rejection as reported by heart transplant patients.

Statement of the Problem

The problem question formulated for this study was: "What mechanisms do heart transplant patients use to cope with rejection of the transplanted donor heart?"

Definition of Terms

For the purpose of this study, the following terms have been defined:

<u>Coping</u> - Lazarus and Folkman (1984) have defined coping as constantly changing cognitive and behavioral efforts to manage specific internal or external demands that are exceeding the resources of the person.

<u>Coping Mechanisms</u> - Sayre (1983) defined coping mechanisms as "operations outside a person's awareness that protect the person against anxiety" (p. 252). Andrews and Roy (1986) defined coping mechanisms as controls of the human system. These mechanisms can be genetically determined or learned and respond to the changing of the environment. For the purpose of this study, coping mechanisms are those operations utilized by transplant patients to deal with a rejection episode. Rejection - Billingham (1979) has classified rejection into four histolologic types: (a) mild rejection is endocardial and interstitial edema with no evidence of myocyte necrosis; (b) moderate rejection is perivascular, endocardial, and interstitial infiltrate associated with muocyte necrosis; (c) severe rejection is extensive interstitial infiltrate associated with myocyte necrosis and vascular necrosis; and (d) resolving rejection is actie fibrosis with residual infiltrate.

Right Ventricular Endomyocardial Biopsy - A right ventricular endomyocardial biopsy (EMB) is an invasive procedure which involves guiding a catheter with a bioptone via the internal jugular vein to the right ventricle to obtain small myocardial specimens for analysis by the pathologist.

Theoretical Framework

The theoretical framework for this study was derived from Roy's (1984) Adaptation Model and Lazarus' (1981) Theoretical Schema of Coping and Adaptation. These theories are described in the following sections.

Roy's Adaptation Model of Nursing

Patients who are experiencing rejection of the transplanted heart are hospitalized and treated medically to reverse the rejection. This event, which deviates from daily lifestyle, requires the patient to adapt or cope with the situation. To assist the patient in adapting, Roy's (1984) Adaptation Model of Nursing addresses the adaptation process in which an individual copes with changing situations.

Roy has defined adaptation, based on the work of Helson, as a function of the degree of change taking place and the person's adaptation level. The person's ability to adapt is dependent on the effect of three stimuli: (a) focal - those immediately confronting the person, (b) contextual - other identifiable stimuli that may influence the person, and (c) residual - those stimuli that influence the person but have not been confirmed. These stimuli determine the range of coping for the person. Roy (1984) defines adaptation level as the changing point that represents the person's ability to respond positively to a situation. The patient with rejection experiences many environmental changes such as leaving the home setting, becoming hospitalized for a period of time, undergoing invasive procedures and medication administration, and experiencing feelings of This degree of change brings about a an uncertain outcome. level of adaptation in which the person must cope with the changing situation. Thus, by identifying the focal, contextual, and residual stimuli and recognizing that each person adapts or copes differently according to the person's level of adaptation, the nurse can provide nursing care according to the needs of the patient.

Roy believes a person copes with stimuli through the use of coping mechanisms. Coping mechanisms are the controls of the human system which may be innate or acquired. Roy further defines innate and acquired coping mechanisms by identifying regulator and cognator subsystems. Regulator coping mechanisms respond automatically through chemical or

neural processes while cognator coping mechanisms respond through four cognitive-emotive channels: (a) perceptual/ information processing, (b) learning, (c) judgment, and (d) emotion (Roy, 1984). The transplant patient in rejection will use both regulator and cognator coping mechanisms.

Behavior is defined in the broadest sense as actions or responses under specified circumstances, either internal or Adaptive behavior results in effective responses external. to stimuli whereas ineffective responses may result in problems or maladaptive behavior. To assess the behavior and/or responses and the adaptation level of the person, Roy (1984) identified four adaptive modes: (a) physiologic, (c) selfconcept, (c) role function, and (d) interdependence. The physiologic mode describes the way the person responds physically to stimuli from the environment. Five needs are identified for physiologic integrity: oxygenation, nutrition, elimination, activity and rest, and protection. The self-concept mode focuses on the psychologic and spiritual aspects of the person. Self-concept directs a person's behavior through the feelings and beliefs the person holds at a certain time. A set of expectations about how a person occupying a position behaves toward another person occupying a position comprises the role function mode. Roles can be classified as primary, secondary, and tertiary. The interdependence mode focuses on interactions related to giving and receiving of love, respect, and value. Roy believes that each person's behavior is viewed in relation to the

four adaptive modes and that they provide the observed manifestations of cognator or regulator coping responses.

In assessing behavior, the nurse identifies how the person is adapting or coping with the situation. The Roy Adaptation Model utilizes a two-level assessment. In firstlevel assessment, the nurse identifies patient behaviors in each of the four adaptive modes. These behaviors are the responses to the changing environment. Second-level assessment involves assessment of the stimuli that are influencing the behavior. Nurses need to be aware of the responses transplant patients exhibit while in rejection and investigate how well the patient is adapting in this particular circumstance.

To gain this information, nurses must seek information from transplant patients on how they cope with rejection by identifying coping mechanisms. With this knowledge, nurses may be able to offer improved nursing interventions to future heart transplant patients who experience a rejection event.

Lazarus Schema of Coping and Adaptation

In an attempt to further define and describe how transplant patients cope with rejection, the investigator has incorporated Lazarus' (1981) Schema of Coping and Adaptation into the framework for this investigation. Lazarus and Folkman (1984) define coping as constantly changing cognitive and behavioral efforts to manage specific internal and/or external demands that are exceeding the resources of the person. In addition, Lazarus and Folkman describe

coping as a multi-dimensional concept in which the degree to which a person experiences feelings of harm or challenge is determined by a cognitive process which is labelled apprai-The coping process has been recognized as problem sal. focused or emotional focused. Lazarus and Folkman have identified situational and personal factors which influence coping and adaptation. Situational factors include social resources, timing of the event, ambiguity, and material Personal factors include beliefs, values, and resources. commitments. All of these variables impact on the person's coping response. Nyamathi (1990) has developed the comprehensive Health Seeking and Coping Paradigm which is based on the Lazarus Schema of Coping and Adaptation and Schlotfeldt (1981) Paradigm of Health Seeking Behaviors. The assumptions of this model are as follows:

- Health seeking and coping is a necessary process which all individuals utilize in various ways throughout their lifetimes.
- 2. Health seeking and coping is understood as being determined by the relationship between the person and the environments.
- 3. Health seeking and coping involves problem-focused and emotion-focused behaviors.
- 4. While individuals have inherent and innate capabilities, some capabilities must be actualized and enhanced through guided learning.
- 5. Nurses can have a major influence on many aspects of the person's health seeking and coping behavior of health outcome.
- 6. The goal of nursing is to utilize knowledge of what is relevant to his health seeking and coping behavior rationally, artfully, and skillfully through use of nursing strategies that assist to realize his maximum potential as it relates to wellness and optimal function (Schlotfeldt, p. 284).

This newly developed framework for nursing offers 12 factors which help determine coping: situational and

personal factors, resources, sociodemographic characteristics, cognitive appraisal health goals, health seeking and coping behaviors, nursing goals and strategies, clients' perceived compliance, clients' perceived coping effectiveness, and immediate and long-term health outcome. Although this framework was not directly used by the investigator, it provided additional support to the theories of coping and adaptation.

In summary, the conceptual framework for this study was developed from two theories. First, Roy's (1984) Adaptation Model of Nursing supports the rationale for describing the coping mechanisms reported by transplant patients in rejection. Knowledge that is gained from the information obtained from these patients during the adaptation process will help nurses to implement the most effective nursing care. Lazarus' (1981) Schema of Coping and Adaptation provides an added understanding of the concept of coping which is the basis of this study.

Significance of the Study

The information ascertained form this research will contribute to nursing knowledge by increasing cardiovascular nurses' understanding of the coping mechanisms utilized by cardiac transplant patients. Health care professionals, especially nurses, are quite comfortable with participating in the medical interventions required to treat the complex complication of rejection. However, less comfort may be experienced in treating the patient's psychological and coping responses to rejection. A description of coping mechanisms

reported by transplant patients will be an important contribution to the nursing care of this patient population. In addition, the documentation of these coping mechanisms will enable nurse educators to communicate this knowledge to other nurses. Information obtained from this study may further substantiate Roy's Adaptation Model which purports that a person adapts to stimuli in the environment.

The effect this information will have on nursing practice cannot go unmentioned. Nursing care of the cardiac transplant patient is highly complex and innovative, requiring dedicated, specialized nurses to manage medical and psychosocial aspects of care. Knowledge of coping mechanisms will enable nurses to formulate specific plans of care which will aim to promote positive coping behavior and will have great value in the nursing specialty of cardiac transplantation.

Assumptions

This study was based on the following assumptions:

1. Cardiac transplant patients utilize coping mechanisms during a rejection episode.

2. Cardiac transplant patients will be honest and open regarding their feelings about rejection.

CHAPTER II

Review of the Literature

Coping has been a topic in nursing and medical literature for many years. There is increasing awareness that people cope with stress or change that is encountered in a crisis or in day-to-day life. While many definitions of coping exist in the literature, all of them refer to the handling, dealing, or managing of a change, stress, or prob-Lazarus (1966) defined coping as constantly changing lem. cognitive and behavioral efforts that manage a problem or regulate the emotional response to a problem. More recently, Holroyd and Lazarus (1982) referred to coping as efforts to manage environmental and internal demands and conflicts. Hansell (1984) described coping as an attempt to gain mastery over conditions of threat. Conversely, Haan (1982) concluded that coping is a good way to handle problems and is not considered a threat or defense. Roy (1984) defined coping as control mechanisms which are central to the functioning of the person. The control processes are termed coping mechanisms. Even with the many definitions of coping, the general consensus is that people do cope with changing situations. There are numerous reported studies in both the nursing and medical literature on how specific populations cope with change, stress, or problems. However,

this investigator could not find any documented study on how cardiac transplant patients cope with the onset of a rejection episode. Studies of coping will be reviewed in this chapter with an emphasis on studies reported in the nursing literature.

Jalowiec and Powers (1981) studied stress and coping in 25 patients with hypertension (chronic illness) and in 25 patients seen in the emergency department (acute illness). It was found by using the Jalowiec Coping Scale (JCS) that both groups utilized problem-oriented coping methods more than affective-oriented coping methods. Problem-oriented coping strategies attempt to deal with the problem or stressor while affective-oriented coping strategies try to deal with the emotions evoked by the problem or stressor. The degree of use is rated from 1 to 5 with end points of never used and almost always used. The highest ranking coping strategies were "hope that things would get better" (affective-oriented) and "try to maintain some control over the situation" (problem-oriented). Both groups rated "seeking help and comfort from significant other" (affectiveoriented) as a middle range method. The lowest ranked coping mechanisms were "take drugs" (affective-oriented) and "let someone else solve the problem" (problem-oriented). These least used coping mechanisms can be classified as negative. Data from this study indicated that different coping behaviors were evident between patients with acute and chronic disease and that a balance of problem-solving

and emotion-regulating coping responses may be needed for a positive outcome.

Baldree, Murphy, and Powers (1982) studied stress identification and coping patterns in 35 hemodialysis patients. Physiological and psychological stressors reported by hemodialysis patients were: limitation of fluid, muscle cramps, fatigue, and uncertainty of the future. Coping behavior was measured by the JCS. The seven most frequently reported coping strategies were hope, maintaining control, prayer and trust in God, looking at the problem objectively, worry, acceptance of the situation, and thinking through different ways to solve the problem. The least used coping methods were blaming or taking out tensions on someone else, use of drugs or alcohol, and letting someone else handle the situa-Patients utilized problem-solving coping strategies tion. more than affective-oriented coping strategies. In a replication of this study, Gurklis and Menke (1988) studied 68 chronic hemodialysis patients. The most frequently reported stressors were feeling tired, limitation of fluid and food, limitations of physical activity, and frequent hospitalizations. Consistent with the findings of Baldree et al., the chronic hemodialysis patients utilized problem-solving coping mechanisms more often than affective-oriented coping mechanisms. The most frequently used coping methods were prayer, maintaining control, acceptance, and hope. Least used coping methods were drinking alcohol, taking drugs, and blaming others.

Childre and Moore (1987) used a qualitative design to study the coping strategies of nine diabetic workers. Three key categories emerged: health, self-image, and feelings about one's work environment. Based on these key categories, three theoretical types of diabetics were classified: decision makers, loyal workers, and fatalists. Decision makers use self-reliant coping mechanisms such as increasing knowledge to improve the situation and considering themselves experts. Loyal workers see their diabetes as making them more vulnerable to rejection by their coworkers. Thus, they use evasive coping strategies like ignoring the problem and trying to put the problem out of their mind. Fatalists are angry because they are a diabetic. They cope with this disease by blaming others, running away from the problem, or accepting the situation because nothing can be done about it. These findings indicate that diabetics cope differently with their disease.

Another qualitative study was conducted by Weems and Patterson (1989) on the coping strategies used by 14 patients awaiting renal transplantation. Two problems were identified in the pre-transplant patient - uncertainty and ambivalence. The investigators concluded that the major underlying coping strategy used by these patients was tempered hope. Peretz (1970) defined hope as the "capacity to anticipate that even though one feels uncomfortable now, one may feel better in the future" (p. 8). Coping methods used in dealing with uncertainty were "when the time comes, it will come" attitude; figuring out a time to expect the surgery; and reminding oneself that the kidney must "match." Worry and expressing gratitude to the donor were ways in which renal patients coped with ambivalent feelings toward the surgery. The investigators concluded that it is important for nurses to recognize coping strategies used by patients who are experiencing uncertainty and ambivalence and to individualize nursing care to promote effective coping during the waiting period.

Sutton and Murphy (1989) reported stressors and coping patterns of 40 renal transplant patients. The stressor scale was modified from Baldree et al. (1982) for use with renal transplant patients. Cost, fear of rejection, and weight gain were identified as the three most reported stressors. Most frequent coping behaviors, as measured by the JCS, were prayer, try to look at the problem objectively, try to maintain control, try to find out more about the situation, and try to draw on past experience to help handle the situation. Problem-solving coping mechanisms were used more frequently than affective-oriented mechanisms; however, when dividing the group into months from transplant (0 to 23 months and 24 to 48 months) the 24- to 48-month group had higher affective-oriented coping scores. Folkman and Lazarus (1980) reported that problem-solving forms of coping increase in situations that are changeable, whereas affective-oriented coping strategies increase in situations in which change is not perceived as a solution. This research documents that early and late transplant patients may cope differently with stressful situations.

Folkman and Lazarus (1980) studied coping in 100 middle-aged men and women in a community. This study was conducted to learn how people coped with stressors in dayto-day life. It was found that over 1 year, both problemsolving and emotion-focused coping were used in 98% of the 1,332 stressful encounters.

Payne (1990) used grounded theory to study 24 women who coped with palliative cancer. All patients were receiving chemotherapy; one-half in the home and the other half in the hospital. Four characteristics emerged form the interviews representing the patients' approach to dealing with chemotherapy: think positive/fighters, acceptance, fearfulness, and hopelessness. It was found that the ways of coping with cancer in this patient population were diverse. For example, reducing awareness of the cancer, denial, diversion, humor, wishful thinking, and anger were a few of the coping strategies.

LaMontagne and Pawlak (1990) studied stress and coping of 30 parents of children in a pediatric intensive care unit. Based on Lazarus' theory, the Ways of Coping Questionnaire and interviews were conducted with the parents. Three themes evolved which described the patients: (a) loss of parenting role, (b) information need, and (c) uncertainty over outcome. The parents used emotion-focused coping (56%) more frequently than problem-solving coping (44%). These findings add important information about how parents cope with their child's stay in the intensive care unit.

Keckeisen and Nyamathi (1990) studied coping and adjustment to illness in 30 acute myocardial infarction patients. Using the JCS, Psychological Distress and the Social Environment Subscales of the Psychological Adjustment to Illness Scale, and the Physiological Symptom Subscale of the Spousal Coping Instrument, it was found that problemsolving coping was used more frequently than emotion-focused coping and that those patients who used problem-solving coping more frequently, had better social and psychological adjustment to illness. Patients with more physical symptoms had poorer psychological adjustment.

Summary

From the information gained in the reviewed literature, it is apparent that people cope with problems, disease, and stressors in every-day life. The coping strategies employed by these different populations may be diverse. There may be differences in coping between acute and chronic illness patients or between treatable and palliable patient populations. At present, nursing literature fails to describe the coping responses of cardiac transplant patients while in rejection. Consequently, further descriptive study is needed to examine how this patient population copes with the stressors of rejection. This information would enable health care professionals to identify coping mechanisms, assess the coping process, and plan individualized nursing care and teaching.

CHAPTER III

Methodology

The purpose of this study was to describe coping mechanisms utilized during a rejection event as reported by heart transplant patients. In this chapter, the methodology of the study is described including design, sample, setting, limitations, instrumentation, data collection, and pilot study.

<u>Desiqn</u>

The design used in this study was a descriptive exploratory survey of the coping mechanisms utilized by heart transplant patients while experiencing a rejection episode. A structured, open-ended interview format was developed by the investigator.

Sample

The sample for this research included six adults who were heart transplant patients and admitted to the hospital with a diagnosis of rejection. It was documented that each subject was treated for acute rejection and that the hospitalization period was at least 3 days. Subjects were required to be at least 18 years of age and able to read and speak English. Subjects who were admitted to the hospital for rejection were excluded from the study if they: (a) were hemodynamically unstable, (b) required admission to the

intensive care unit; or (c) were placed in protective isolation. All six subjects approached by the investigator participated in the study. There were no subjects who refused to participate.

Setting

This study was conducted in a large university medical center located in the Southeastern United States during the spring of 1990. Adults 18 years of age or older who had undergone cardiac transplantation, were hospitalized with the diagnosis of rejection, and who agreed to participate were included in the study.

Limitations

The following limitations were identified for this research:

1. Subjects varied regarding the length of hospital admission and the type and dosage of anti-rejection medicine prescribed which may have influenced the responses to the questions.

2. No effort was made to control for discussion of coping mechanisms during rejection among subjects.

3. The subjects knew the investigator prior to the study, and their responses to the questions may have been altered by this relationship.

4. The sample size is small because many subjects who would have been eligible for this study were participating in another large-scale study.

Instrumentation

The development of the data collection instrument was aimed at answering the research question: "What mechanisms do heart transplant patients use to cope with rejection of the transplanted donor heart?" The investigator concluded that a one-to-one interview with open-ended questions would allow useful information to emerge (see Appendix A).

The interview tool consisted of eight open-ended items associated with the event of rejection. For example, one item was, "Describe how you cope with rejection." Openended items provided the subjects with the opportunity to respond in detail and for the investigator to clarify any ambiguity.

In addition to the interview tool, the Jalowiec Coping Scale (JCS) was utilized to rank order the coping mechanisms selected most often by the heart transplant patients while in rejection. The JCS is derived from a 60-item scale of coping strategies (see Appendix B). The degree of use is rated from 1 to 4 with end points of never used and often used (Jalowiec, Murphy, & Powers, 1984). Jalowiec and Powers (1981) reported a Cronbach's alpha reliability coefficient of .86 (N-141) and .95 (N-15). Content validity has been demonstrated by the manner in which the tool was developed, by the large number of items, and by the diverse coping behaviors. Construct validity is supported by the reported alpha coefficients and the ongoing factor analysis of this tool. The purpose in using this scale was to help

the subjects recall any coping mechanisms that might not have been remembered during the interview.

Pilot Study

A pilot study was conducted by this investigator to test the study procedure. No changes were made in the study protocol after the initial subject was entered.

Data Collection Procedure

Prior to the initiation of this research, an informal survey of transplant coordinators, clinical nurse specialists, and health professionals involved in cardiac transplantation was conducted to determine the need for this information. It was concluded from this survey that many professionals did not think about the coping mechanisms which patients used during rejection, whereas much thought went into how to treat the rejection. It was concluded that knowledge of how transplant patients coped with rejection would be valuable for nursing and medical practice.

Before initiating data collection, permission to conduct the study was obtained form the director of cardiac transplantation. Also, permission to conduct the study was granted from the Institutional Review Board for Human Use (IRB) at this university medical center.

The study was conducted between the months of March and May, 1990. Potential subjects were identified by the hospital admission diagnosis. Subjects who were eligible and able to be interviewed were visited by the investigator within 48 hours of admission. Informed consent was obtained from each subject at this time. Subjects were informed that the interview would be recorded on cassette tapes to insure accuracy and that anonymity would be maintained by the assignment of a study number for identification purposes. When it was determined that the subject was eligible, interviews were conducted in the patient's private room with only the patient and interviewer present.

Immediately following the interview, the JCS was distributed to the subject and verbal instructions were provided by the investigator to aid in the completion of the questionnaire. The subjects were informed that the investigator would collect the questionnaire within 24 hours and would be available if the subjects had any questions about the tool.

Subjects described the experience of coping with rejection in their own words and completed the Jalowiec Coping Scale. Demographic data were obtained from the medical records (see Appendix C).

CHAPTER IV

Presentation of Findings

The purpose of this study was to describe the coping mechanisms utilized during rejection as reported by heart transplant patients. Within this chapter, an overview of the sample is presented. Case presentations of each subject are reported, each subject's responses to the interview items is described from the transcribed recording of each interview, and the results from the JCS are described according to the frequency of use.

Overview of the Sample

All of the subjects interviewed for this study received a heart transplant and were admitted to the hospital with the diagnosis of rejection. Of the five males and one female in this sample, three patients were transplanted due to coronary artery disease and three due to dilated cardiomyopathy. The ages for the sample ranged from 27 to 54 years, with a mean age of 44 years. Time from transplant of the sample ranged from 5 months to 74 months, with a mean time of 34 months. An overview of the sample by subject is presented in Table 1.

Subject	Sex	Age	Indication for Heart Transplant	Transplant Date	Number Treated Rejection Episodes Prior to Present Rejection
н	ſц	52	Dilated Cardiomyopathy	3/29/87	L
2	W	49	Coronary Artery Disease	1/12/90	2
m	¥	34	Dilated Cardiomyopathy	9/28/85	1
4	W	54	Coronary Artery Disease	7/27/89	8
ß	W	51	Coronary Artery Disease	9/22/88	4
9	Ж	27	Dilated Cardiomyopathy	4/24/84	8

Table 1 <u>Overview of Sample</u>

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Case Presentation of Individual Subjects Subject No. 1

Subject No. 1 was a 52-year-old, white female who was admitted to the hospital for acute rejection. One month prior to this admission, she was treated for moderate rejection as an outpatient with high dose oral Prednisone. On the day of the present biopsy (March 5, 1990), she was feeling "a little more tired than usual" and had a low grade fever. Because of her recent rejection, it was decided she should be admitted and receive Methylyprednisone pulse therapy and Methotrexate. After one dose of Methotrexate 2.5 mg, she developed excruciating lower back pain, renal insufficiency, and profound leukopenia. The Methotrexate was discontinued. After 3 days of Methylprednisone, she was biopsied and found to be in moderate rejection again. An additional course of Methylprednisone pulse therapy was given; however, after biopsy 3 days later, she remained in Therefore, 2 days of intramuscular RATG was adrejection. ministered. On re-biopsy on March 13, 1990, her rejection had subsided. The investigator visited the patient on the day after admission. The following are verbatim excepts of the recorded responses of Subject No. 1 during the interview:

- <u>Item 1</u>: What does rejection of your heart mean to you?
- <u>Response</u>: I know what's gotta be done. It used to bother me a whole lot. I get tired of being in the hospital.
- <u>Item 2</u>: How do you feel when you are called and told you have rejection?

<u>Response</u>: Upset and sad, but then it gets better.

Item 5: Describe how you cope with rejection

<u>Response</u>: I think I do good. I pray a lot and I think that helps.

<u>Item 6</u>: What are some things you do in order to help you cope with rejection?

<u>Response</u>: Stay busy. I cry when I first find out and then I'm okay.

Subject No. 2

Subject No. 2 was a 49-year-old, white male who underwent cardiac transplantation 2 months previously and was admitted to the hospital with acute rejection. He had a rejection episode just 10 days earlier an it was determined that RATG therapy for 3 days would be the best treatment option for him at the time. The investigator visited the subject on the day after admission. The following are verbatim excepts of the recorded responses of Subject No. 2 to the items in the interview:

<u>Item 1</u>: What does rejection of your heart mean to you?

Response: It doesn't match exactly.

- <u>Item 2</u>: How do you feel when you are called and told you have rejection?
- <u>Response</u>: Depressed. A feeling of not again. Upset. I want to go back home.
- <u>Item 4</u>: Are there things you do not like about rejection?
- <u>Response</u>: Going back into the hospital. You don't have control over your own destiny.
- Item 5: Describe how you cope with rejection.
- <u>Response</u>: I haven't discovered how to cope with it yet. You put up with it.

- <u>Item 6</u>: What are some things you do in order to help you cope with rejection?
- <u>Response</u>: You either say, hey, I'm handling this or I'm not handling this.

Item 7: How do you feel about biopsies?

<u>Response</u>: Biopsies are a pain in the neck, literally. <u>Subject No. 3</u>

Subject No. 3 was a 34-year-old white male who was admitted to the hospital for acute rejection which was diagnosed from a routine biopsy. The subject had no signs or symptoms of rejection. This was the first rejection episode this patient had since his transplant in 1985. He was treated with oral Prednisone for 3 days in the hospital and then discharged on a Prednisone tapering schedule. One week later he was re-biopsied and was again diagnosed as having acute rejection; therefore, he was re-admitted and treated with Methylprednisone pulse therapy. On the day after the first admission, the investigator interviewed the subject. The following are verbatim excerpts of the recorded responses of Subject No. 3 during the interview:

- <u>Item 1</u>: What does rejection of your heart mean to you?
- <u>Response</u>: If means my body is trying to destroy my heart. I'll possibly have to get another heart or I'll die.
- <u>Item 4</u>: Are there things you don't like about having rejection?
- <u>Response</u>: No symptoms. Having to come to the hospital. Terrible treatments. It's an imposition.

Item 5: Describe how you cope with rejection.

- <u>Response</u>: Okay. I'm in the best place for treatment. Right now it's just an imposition with my normal daily activities.
- <u>Item 6</u>: What are some things you do in order to help you cope with rejection?
- <u>Response</u>: Pray a lot. Increase time with family and friends try to that is.
- <u>Item 8</u>: Are there some rejection treatments that are more stressful to you?
- <u>Response</u>: Yes. Lying in bed with an IV hooked up to you. The medicine can change your appearance. Going back and forth to the hospital.

On the second admission for Subject No. 3, the investigator decided that re-interviewing the subject might provide useful information. On the day following his second admission for rejection, the investigator conducted a second interview. The following are verbatim excerpts of the recorded responses of Subject No. 3 to the items during the second interview:

<u>Item 1</u>: What does rejection of your heart mean to you?

<u>Response</u>: My body is trying to kill my heart.

- <u>Item 3</u>: Describe how you feel when you have more than one rejection episode.
- <u>Response</u>: The treatment that I got stopped the rejection and then a week or so later, I got another rejection. Something was going on that scared me so I worry and pray the doctors will stop it for good.
- <u>Item 6</u>: What are some things you do in order to help you cope with rejection?
- <u>Response</u>: It's nice to have people to talk to who are going through the same thing. Spend time with family, friends, and other patients.

Subject No. 4

Subject No. 4 was a 54-year-old white male admitted to the hospital for acute rejection. His immediate postoperative course was complicated by multiple rejection episodes which were treated with multiple immunosuppressive agents such as intravenous mythylprednisolone, intramuscular rabbit antithymocyte globulin (RATG) and methotrexate. He is presently undergoing total lymphoid irradiation (TLI) and Methylprednisolone pulse therapy. A summary of his moderate rejection history can be seen below:

Dates of Moderate Treatment Rejection 8-12-89 Methylprednisolone 500 mg X 1 8-21-89 Methylprednisolone 1000 mg daily X 3 9-21-89 Methylprednisolone 1000 mg daily X 3 10-02-89 RATG 100 mg daily X 3 10-05-89 RATG 100 mg daily X 2 Methylprednisolone 1000 mg daily X 3 10-12-89 Methylprednisolone 1000 mg daily X 3 11-06-89 Methotrexate 2.5 mg every 8 hours for three doses once weekly for 3 weeks 1-08-90 Methylprednisolone 1000 mg daily X 3 1-11-90 Methylprednisolone 1000 mg daily X 3 2-04-90 Methylprednisolone 1000 mg daily X 3 Begin TLI 3-21-90 Methylprednisolone 1000 mg daily X 3

On the day following the most recent rejection episode, the investigator interviewed the subject. The following are verbatim excerpts of the recorded responses of Subject No. 4 to the interview.

- Item 2: How do you feel when you are called and told you have rejection?
 Response: Disappointed, very. Irritable.
- Item 5: Describe how you cope with rejection.
- <u>Response</u>: It think I do as well as anyone. I try to be realistic about the situation.

<u>Response</u>: I try to put things in perspective.

Subject No. 5

Subject No. 5 was a 51-year-old white male admitted to the hospital for treatment of acute rejection with Methylprednisolone pulse therapy. The rejection was diagnosed by a routine biopsy and the subject had not experienced any signs or symptoms of rejection. The following are verbatim excerpts of the recorded responses of Subject No. 5 to the items during the interview:

- <u>Item 1</u>: What does rejection of your heart mean to you?
- <u>Response</u>: It takes you out of a routine you've got adjusted to and your livelihood is interrupted. I get a little irritated from the fact that it takes me away from something I want to do.
- <u>Item 2</u>: How do you feel when you are called and told you have rejection?
- <u>Response</u>: The bottom just drops out and then you have to reach back and get some willpower and motivation to put yourself in a different mood. The quicker you can do that, the better you are. Try to build yourself up. It's easy to get depressed. I'm doing find. I feel good and it hits you. The further out you go and the longer it is, the harder it hits you when you have rejection. The type personality you have has a lot to do with it - it's worse on Type A personalities, which I am.
- <u>Item 3</u>: Describe how you feel when you have more than one rejection episode?
- <u>Response</u>: You never get to the point where you got it made now. I'm out 2, 3, 4, months and still can have rejection. Every time the phone rings, you think, oh no I got to go back to the hospital.

- Item 4: Are there things you don't like about rejection?
- <u>Response</u>: Reverse isolation the whole world is closing in on you.
- Item 5: Describe how you cope with rejection.
- Response: I think okay after I accept it. The first 2 to 3 hours are tough. It is best to be around someone you can shoot the breeze with, kid, and joke.
- <u>Item 6</u>: What are ome things you do in order to help you cope with rejection?

Response: Be around somebody you can talk to.

Subject No. 6

Subject No. 6 was diagnosed to be in acute rejection and admitted to the hospital for Methylprednisolone pulse therapy. This particualr patient had not taken his immunosuppressive medicine for several days and was experiencing symptoms of tiredness, dyspnea, and pedal edema. The investigator interviewed the subject on the day of admission. The following are verbatim excerpts of the recorded responses of Subject No. 6 to the items during the interview:

- <u>Item 1</u>: What does rejection of your heart mean to you?
- <u>Response</u>: It means something is wrong. There's trouble with my heart and needs to get seen about.
- Item 5: Describe how you cope with rejection.
- <u>Response</u>: I don't know if I cope with rejection at all. I guess it's bad, but I try not to even think about it. I put my confidence in the doctors because they'll straighten it out. I guess I accept the situation because it has to be taken care of.
- <u>Item 6</u>: What are some things you do in order to help you go with rejection?

<u>Response</u>: I don't think about it. I think about other things. I just think that the next biopsy will be good.

Findings

Based on the descriptions of the coping mechanisms utilized as reported by six heart transplant patients who were admitted to the hospital for rejection, the following findings are summarized:

1. Five of six patients reported that they coped with rejection. One subject (No. 2) thought he hadn't discovered how to cope with rejection yet, but reported that he had to put up with it.

2. All six subjects reported that being admitted to the hospital was what they did not like about rejection. Subject No. 3 stated "imposition with normal daily activities." Subject No. 5 reported "it takes you out of a routine you've got adjusted to . . ."

3. Subject Nos. 1 and 3 reported they prayed during rejection to help them cope with the situation.

5. All subjects reported feeling sad, depressed, upset, or irritable when they found out they were in rejection.

Jalowiec Coping Scale Findings

Based on the tabulation of coping mechanisms listed in the Jalowiec Coping Scale which was completed by each subject, the coping strategy findings were as follows:

 The most used coping strategies were hoped that things would get better and prayed or put your trust in God.
 Five of six subjects reported using these strategies. 2. Four of six subjects reported using these coping mechanisms: tried to keep the situation under control, tried to handle things one step at a time, tried to keep your life as normal as possible and not let the problem (rejection) interfere, told yourself not to worry because everything would probably work out fine, tried to distract yourself by doing something that you enjoy, tried to think positively and wished the problem (rejection) would go away.

3. The least used coping mechanisms were: told yourself that the problem (rejection) was someone else's fault, had a drink, did something impulsive or risky, and blamed yourself for getting into such a situation.

4. Subject No. 5 wrote a coping mechanism in the space provided at the end of the scale. He wrote the following: "Think about longer periods of time between rejection. Don't get trapped in short term plans because of fear of rejection, but keep an alternative plan". He often used this strategy to help him cope with rejection.

5. Worried about the problem and wanted to be alone to think things out were not selected by any subject as coping strategies.

6. Subject No. 2, who reported that he had not discovered how to cope with rejection yet identified one coping strategy as most often used: tried to keep the situation under control.

Table 2 presents the rank ordering of the coping strategies identified from the JCS. The investigator did not measure the perceived effectiveness of these coping mechanisms.

<u>Rank Ordering of Degree of Use of 60 Items on the</u> <u>Jalowiec Coping Scale of Six Cardiac Transplant Patients</u>

Coping Strategy	Number of Patients Using This Strategy (N = 6)
Prayed or put your trust in God Hoped that things would get better	5 5
Wished the problem would go away	4
Tried to keep the situation under control	ol 4
Tried to handle things one step at a tim Tried to keep your life as normal as pos	ne 4
and not let the problem interfere Thought about how you had handled other	4
problems in the past Told yourself not to worry because	4
everything would probably work out fi	
Waited to see what would happen Tried to distract yourself by doing	4
something that you enjoy	4
Tried to keep a sense of humor	4
Tried to think positively Tried to get away from the problem	4
for awhile Accepted the situation because very litt	3 :le
could be done	3
Tried to find out more about the problem	
Tried to keep your feelings under contro Told yourself that you could handle	
anything no matter how hard	3 3 3
Thought about good things in your life	3
Preferred to work things out yourself Compared yourself with other people who	-
were in the same situation	3
Tried to work out a compromise	2
Let time take care of the problem Talked the problem over with people who	2
had been in a similar situation Thought out different ways to handle	2
the situation	2
Told yourself things could be worse	2 2
Exercised or did some physical activity	2
Got mad and let off steam Talked the problem over with family or	2
friends	2

Coping Strategy	Number of Patients Using This Strategy (N = 6)
Tried to put the problem out of your min and think of something else Tried to look at the problem objectively	2 Y
and see all sides Practiced in your mind what had to be de Tried to keep busy and work harder	2
Tried to see the good side of the situal Depended on others to help you out Tried to change the situation	2
Slept more than usual Used relaxation techniques	2
Set up a specific plan of action Learned something new in order to deal with the problem	1
Tried to improve yourself in some way so you could handle the situation	1
Worried about the problem Wanted to be alone to think things out	0 0
	<u>Never Used</u>
Told yourself that you were just having some bad luck Daydreamed about a better life Talked the problem over with a profession	
person (such as a doctor, nurse, min teacher, counselor) Kept your feeling to yourself	ister, 1 1
Avoided being with people Took medications Prepared for the worst that could happen	2 2 1 2
Took out your tensions on someone else	2
Put off facing the problem Tried to get out of the situation Resigned yourself to the situation	3 3
because things looked hopeless Ate or smoked more than usual Tried to ignore or avoid the problem	3 3 3
Told yourself that this problem was real not that important	ly 3

Coping Strategy	Number of Patients Using This Strategy (N = 6)
	Never Used
Did something risky or impulsive	4
Blamed yourself for getting into such a situation	4
Told yourself that the problem was some else's fault Had a drink	one 5 5

Summary

An overview of the sample was given in this chapter identifying the sex, age, indication for transplant, transplant date, and number of rejection episodes prior to the current episode. Case presentations of the subjects who were admitted to the hospital for rejection were reviewed. Following the case presentation, the individual responses to the items on the interview were given verbatim. Lastly, the Jalowiec Coping Scale was handed to the patient to complete and the investigator collected the tool during the next 24 hours.

CHAPTER V

Conclusions, Discussion, and Recommendations The aim of this study was to describe the coping mechanisms utilized during rejection as reported by heart transplant patients. The study question was: "What mechanisms do heart transplant patients use to cope with rejection of the transplanted donor heart?

The sample consisted of one adult female and five adult males who were admitted to a large university medical center in the Southeastern United States with the diagnosis of rejection. The investigator conducted interviews with each of the subjects for approximately 30 to 45 minutes. An 8-item interview tool was utilized and the interview was recorded on cassette tapes. The data were presented as verbatim responses by the subjects. After the interview, the JCS was administered and completed by each subject.

<u>Conclusions</u>

Based on the findings of this study, the following conclusions have been drawn:

1. The majority of the subjects interviewed in this study identified mechanisms to help them cope with rejection.

2. The most frequently used coping mechanisms were "prayer" and "hoped things would get better."

3. The least frequently used coping mechanisms were "told yourself that the problem was someone else's fault" and "had a drink."

4. All subjects felt sad or depressed when they were told they had rejection.

5. All subjects reported that admission to the hospital was the worst thing about rejection.

Discussion

As in the studies by Baldree et la. (1982) and Sutton and Murphy (1989), the subjects in this study utilized coping mechanisms to help them cope or adapt to the situa-In the study by Sutton and Murphy, prayer was used by tion. kidney transplant patients and was one of the top three most frequently used coping strategies. Also consistent with the findings from the present study is the study by Baldree et al. in which prayer and hope were among the top five most frequently used coping mechanisms. The least frequently used coping mechanisms were similar in both the renal transplant and hemodialysis population. In the present study, the results were also similar in that the least frequently used coping strategies were blaming someone else and drink-The subjects in the present study did not use coping ing. strategies such as trying to find out more about the situation or try to draw on past experiences to help them cope, whereas in the studies by Sutton and Murphy and Baldree et al. with kidney transplant and hemodialysis patients, frequently used these coping mechanisms. An explanation for this finding may be the follow-up time from transplant. It

is possible that a shift in coping styles occurs as the time from transplant lengthens. The findings of the present study are consistent with the work of Folkman and Lazarus (1980) in that problem oriented methods increase in situations that are changeable and affective-oriented methods are used in situations in which change is not perceived. Heart transplant patients who are several years from transplant may perceive the situation differently and, therefore, cope differently with the situation of rejection.

Although this study did not focus on identification of stressors related to rejection, it is interesting to note that all subjects reported being admitted to the hospital as "the worst part" of rejection. This response could be viewed as a stressful experience for these patients. Also, Subject No. 5, who wrote "don't get trapped in short term plans because of fear of rejection" as a coping strategy could be reporting fear of rejection as stressful.

Christopherson (1987) summarized the heart transplant experience as follows:

Realistically, not (transplant patients) had an "easy" course. Neither they nor their families escaped the anxiety and pain of the transplant process and all have lost friends who were also recipients through the intervening years. Some have themselves experienced life-threatening complications. Yet, from a number of prospectives, the worry, fear, and upheaval of transplantation were worth it, not only for the recipients and families, but also for the physicians and hospital staff who worked so hard to achieve patient survival and independence (p. 62).

All six subjects in this study were confronted with a changing situation. All subjects were required to leave their home environment, become hospitalized, and undergo

treatment for the diagnosis of rejection. According to Roy (1984), an individual adapts to stimuli through the use of coping mechanisms. By utilizing Roy's Adaptation Model, the nurse can identify patient behaviors, assess the stimuli affecting the behavior, and then select and carry out appropriate nursing interventions. For example, in this study, the most frequently used coping strategies reported by patients in rejection were prayer and hope. Based on this information, the nurse providing care for these patients might promote hope and consult clergy to visit patients daily while in rejection.

As previously described, Lazarus' (1981) coping and adaptation theory contributed to the framework for the study. Lazarus and Folkman (1984) believe coping occurs when the person cannot routinely handle the demands of the situation and must draw on something else. Adaptation refers to how well the person adjusts to situations. According to Lazarus' theory, the transplant patients adapt with the situation of rejection by using coping mechanisms. Limitations of the Interview

Because of another ongoing study, many of the potential subjects who were recent transplant patients (0 to 6 months) were not included in the study. Inclusion of these patients may have elicited different coping responses.

In conducting the interviews in this study, the investigator experienced difficulty in having the subject answer the questions directly. For instance, Subject No. 1 responded to the question, "What does rejection of your heart

mean to you?" by stating, "it used to bother me a lot, but now not as much." Perhaps an unstructured interview tool would have allowed the investigator more flexibility in probing for additional information.

The interview tool did not directly ask the subject what was stressful about rejection. It would have been helpful to identify stressors associated with rejection and how the subjects coped with these stressors. Further investigation is needed in this area.

Recommendations

Based on the conclusions of this study, the following Recommendations are offered in the areas of nursing practice, research, and education:

<u>Practice</u>

Since the subjects in this study reported the use of mechanisms to help them cope with rejection, it is recommended that health care professionals caring for heart transplant patients identify the patients' individual coping strategies. By identifying these coping methods, nurses can develop, implement, and evaluate interventions that foster positive outcomes. In this study, the most common coping methods were prayer and hope. Thus, the nurse may need to direct the patient to supports such as clergy or social services, utilize effective listening and therapeutic touch, and offer realistic hope to these patients.

Research

This study should be replicated with the following changes:

1. Collection of data should include recent and longterm transplant patients to evaluate any differences in coping strategies. Also, the study should have a larger sample size.

2. The study should include questions in the interview asking for identification of stressors.

3. The interview tool should be revised to allow for more verbal exchange between the interviewer and subjects. Education

It is recommended that nurses who are caring for heart transplant recipients complete an orientation program regarding the process of transplantation and the coping and adaptation that is reported by patients undergoing this process be reviewed. Nurses need to be aware of the psychological impact that complications such as rejection may have on the patient. Knowledge of the coping process used by these patients would enable nurses to provide better care by meeting both the physiological and psychological needs of the patient.

Summary

The conclusions from this study have been presented and discussed in relation to the literature and theoretical frameworks. Limitations encountered during the study have been described. Lastly, recommendations based on the findings were made in the areas of nursing practice, research, and education.

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Appendix A

Structured Interview

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Structured Interview

- 1. What does rejection of your heart mean to you?
- 2. How do you feel when you are called and told you have rejection?
- 3. Describe how you feel when you have more than one rejection episode.
- 4. Are there things you do not like about having rejection?
- 5. Describe how you cope with rejection.
- 6. What are some things you do in order to help you cope with rejection?
- 7. How do you feel about biopsies?
- 8. Are there some rejection treatments that are stressful to you?

Appendix B

Jalowiec Coping Scale

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Appendix C

Data Sheet

″*3 * Data Sheet

Subject Number:	 Date:	
Consent signed:	 	
Sex:	 Age:	
Transplant Date:	 	
Marital Status:		
Single Married Widow/W Separat		
Hospital Course:	 	

UNIVERSITY OF ALABAMA SCHOOL OF NURSING UNIVERSITY OF ALABAMA AT BIRMINGHAM MSN DEGREE PROGRAM THESIS APPROVAL FORM

Name of Candidate	Connie White-Williams	
Major Subject	Cardiovascular Nursing	
Title of Thesis	Coping Mechanisms Reported by Cardiac Transplant	
	Patients in Acute Rejection	
	:	

Thesis Committee:		
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MSN Chairman <u>T. Stullenbr</u>	ann	
Associate Dean, Graduate Programs		

2/18/41 Date ____