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Validation of an instrument measuring maintenance of hope in heart transplant patients

Fasbinder, Laurie Guyton, M.S.

The University of Arizona, 1991
VALIDATION OF AN INSTRUMENT
MEASURING MAINTENANCE OF HOPE
IN HEART TRANSPLANT PATIENTS
by
Laurie Guyton Fasbinder

A Thesis Submitted to the Faculty of the
COLLEGE OF NURSING
In Partial Fulfillment of the Requirements
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In the Graduate College
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1991
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This thesis has been approved on the date shown below:

MERLE H. MISHEL
Professor of Nursing

[Signature]  
July 22, 1947  
Date
DEDICATION

I would like to dedicate this thesis to my husband, Dennis, for his loving encouragement and excellent typing skills during my educational endeavors. Also to my daughters, Jennifer, Kelly and Adrienne, for all the distractions that they have provided.
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I would like to express my gratitude to several people who were instrumental in helping me complete my thesis.

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ABSTRACT

The purpose of this study was to revise and expand the Hope Maintenance Scale. An exploratory design was used to content analyze qualitative data collected from 226 heart transplant patients in the primary study, "Predictors of Quality of Life in Heart Transplantation". Results supported five of the six original dimensions of hope contained in the Hope Maintenance Scale. The five dimensions substantiated were: Downward Comparison, Fostering Optimism, Belief in a Powerful Other, Avoiding Painful Situations or Material, and Viewing the Situation as Temporary. Subcategories for the dimension of optimism were generated and termed: Forced Optimism, Guarded Optimism, Euphoria, and Gratefulness. The subcategory of Exceptional Experience was developed for the category of Downward Comparison. Normalizing was proposed as an antecedent of hope. Of subjects who expressed normalizing activities, 60% also used other hope maintenance strategies. Of subjects who reported Threats to Normalizing, 42% used no other hope maintenance strategies.
CHAPTER 1

Introduction

From the first orthotopic cardiac transplant in 1967 to the present, heart transplantation has advanced dramatically. The National Organ Transplant Act of 1984 provided for centralized sharing of data concerning available donor organs and transplantation statistics (Kriett & Kaye, 1990). As a result of this legislation, heart transplantation is no longer considered experimental, a fact which facilitates reimbursement by Medicare and third party insurers.

The Registry of the International Society for Heart Transplantation reported that a total of 12,600 heart transplantations had been performed as of December 31, 1989. More than 85% of these have been performed since 1985 (Kriett & Kaye, 1990).

Patients who become heart transplant recipients currently experience increasingly successful surgeries due to their careful and conservative selection as candidates. The use of cyclosporine in combination with other immunosuppressive and steroidal agents, has also contributed to the increased postoperative survival rates. The effort to improve survival rates post-transplant continues. However, survival is not the sole indicator of successful surgery. Quality of life after heart transplantation is a variable that must be examined to determine the benefits of
surgery. Documentation is needed which describes the experience of living with heart transplantation from the perspectives of the recipient and the family.

The post-transplant period is marked by physical and psychological stresses which are unique to the recipient and family (Macdonald, 1990). Problems may include the ongoing possibility of medical complications such as infection or rejection of the donor heart. Costs of medication and long-term health care, along with the potential inability to work, provide financial difficulties (Macdonald, 1990). The patient's role in the family is altered, which results in adjustments in family interactions (Jones et al., 1988; Michalisko, 1990). Finally, the uncertainty about the recipient's long-term survival provides further stress (Macdonald, 1990).

Maintenance of hope throughout the transplant process is postulated as one strategy utilized by patients and their partners to cope with physical and psychological stressors. The influence of hope on the quality of life of family members following the patient's heart transplantation was examined by Mishel and Murdaugh (1987). Qualitative data were collected during family support groups. From the data, a Hope Maintenance Scale was developed. The scale measures methods used by family members to restore and maintain hope while faced with the adjustments and unpredictability of transplantation.
In the follow-up study entitled "Predictors of Quality of Life in Heart Transplantation" (Murdaugh & Mishel, 1988), the Hope Maintenance Scale was used in a multiple clinical site study of recipients of heart transplantation and their significant others. The purpose of the study was to test a conceptual model to explain the quality of life in transplant patients and their partners. Following completion of the questionnaire booklet, subjects were asked to use the final page of the booklet to describe their experience of living with heart transplantation. Because data were collected in the form of written responses to an open-ended statement, it directly reflected the concerns of the patient.

The purpose of the current study was to further refine the Hope Maintenance Scale using subjects' responses to the open-ended statement in the "Predictors of Quality of Life in Heart Transplantation" study. An overview of the problem and the purpose and significance of this study are presented in the following sections.

**Overview of the Problem**

The increase in clinical experience in heart transplantation has led to improvements in immunosuppressive agents, surveillance for infection and rejection, patient selection, and in long-distance donor procurement (Barnhart & Lower, 1988). These factors have contributed to the decreasing mortality rate post-transplant. Current survival
rates for 1 year are 81% and for 5 years, 72% (Kriett & Kaye, 1990). Rejection of the heart and infection remain the major causes of transplant mortality (Baldwin, Wolfgang, Shumway, & Lower, 1989).

When a transplant candidate receives the awaited heart, it is viewed as a cure for all their problems. Their hope for a chance for the future is renewed. Few patients and partners are aware that transplant surgery marks the time when the real battle begins (Augustine, 1990). Patients and partners are required to learn about medical complications, effects and side effects of medications, responsibilities for follow-up care and for adherence to treatment regimens, and the psychosocial adjustments associated with heart transplantation.

Medical complications of major risk are infection and rejection. To decrease the chance of infection immediately postoperatively, the patient is maintained in isolation in the intensive care unit until all lines and tubes are removed (Baldwin et al., 1989). Over the months following transplantation, the patient is carefully observed for signs and symptoms of infection.

Rejection of the donor organ also requires aggressive surveillance and intervention. The immunosuppressive drugs, cyclosporine and azathioprine, are administered in combination with steroids, so-called triple therapy, to prevent or treat rejection. The usefulness of these drugs
to combat rejection is modified by the associated side effects of renal and hepatic impairment, weight gain, hypertension, accelerated atherosclerosis, and malignancy (Baldwin et al., 1989). The patient must maintain strict adherence to treatment regimens to decrease the potential for medical complications, while in the hospital and after discharge.

Finally, the patient and family must also adjust to the psychosocial changes throughout the transplant process. Specific stages of psychological adjustment have been described by Allender, Shisslak, Kaszniak, and Copeland (1983) as the evaluation period, the waiting period, the immediate post-surgical period, the first rejection episode, the recovery period, and hospital discharge. During the evaluation period, the patient's prospect for transplantation is explored. The waiting period finds patients worrying that they will not receive a donor heart in time. The immediate post-surgical period reveals a renewed enthusiasm for the future. The first rejection episode is an inevitable milestone that produces anxiety. The recovery period is associated with a range of emotions as progress and setbacks are experienced. The hospital discharge period is one of ambivalence as the patient resumes independence.

Others have described stages of psychosocial change that coincide with those of Allender et al.; O'Brien, 1985;
Watts et al., 1984). Some authors (Christopherson, 1987; Macdonald, 1990) have added a post-discharge stage in recognition of the long-term psychological adjustments that occur post-transplant. Mishel and Murdaugh (1987) identified stages of psychosocial adjustment that are manifested in changing family interactions. Both recipient and family members experienced reciprocal psychological changes.

There are several areas of psychological adjustment necessary after transplantation. Health status, marital and family status, and employment and financial status are three dominant areas which affect the recipient's psychological adjustment (Macdonald, 1990).

Physical health status changes directly influence psychological health status (Macdonald, 1990). Infection and rejection are the most common medical complications experienced by transplant recipients, but graft atherosclerosis and malignancy may also develop (Baldwin et al., 1989). In addition, physical changes may occur as a result of steroid and immunosuppressive therapy. Distressing side effects include hirsutism, weight gain, emotional lability, and cushingoid appearance of the face (Michalisko, 1990). Impotence and decreased interest in sex were reported by Lough, Lundsay, Shinn, and Stotts (1987) as the most distressing symptoms described by patients. Medication side effects impact the patient's body- and

Marital and family status is altered in several ways post-transplant as described by Mishel and Murdaugh (1987). Family roles are adjusted during the transplant period in a process the authors called "redesigning the dream". This process occurs when adjustments must be made to a new type of life and future. The contribution of family to quality of life is identified by recipients as the most important factor (Lough et al., 1985).

Finally, financial status is also altered. The costs of transportation and housing associated with treatment at a distant transplant center, may be compounded by the recipient's inability to return to work. Many patients desire employment, and are physically able to work, but are unable to do so due to employer or insurance restrictions (Lough, 1988). Financial difficulties along with physical and family changes combine to affect psychological adjustments and also quality of life post-transplant.

Underlying all stages of the transplant process is unpredictability, which further affects psychological adjustment. Recipients are faced with an uncertain chance of survival before a donor heart can be found. Their life is complicated post-transplant by the uncertainty of medical, psychological, and financial stability.
Recipients and family members must learn to live with the uncertainties of the future because transplantation postpones death for an unknown length of time (Caine & O'Brien, 1989). A great degree of uncertainty is associated with coping and adjustment difficulties (Christman, 1990; Mishel, Hostetter, King, & Graham, 1984). Usual coping strategies may not always be adequate to adjust to the uncertainty (Weems & Patterson, 1989).

Maintenance of hope is posited as one method used to facilitate coping with the physical and psychological stressors (Weems & Patterson, 1989). Recipients and their partners develop and utilize strategies to bolster their level of hope. Hope maintenance is defined by Murdaugh and Mishel as "the cognitive appraisal of transplant-related events so that a positive evaluation emerges" (1988, p. 40).

The Hope Maintenance Scale was developed from qualitative data collected from recipients' family members concerning their experiences of living with heart transplantation. Data were collected in the form of audiotaped interviews during 36 family support group sessions. Utilizing grounded theory methodology, the data were concurrently collected, coded, and analyzed. Themes that emerged from the data were grouped into categories, which emerged as six dimensions of hope. Only statements receiving 100 percent agreement between investigators were written into items. Each dimension of hope was developed
into items that comprise the Hope Maintenance Scale. A standardized Cronbach's alpha coefficient for the scale was reported as .91. The six dimensions described by Murdaugh and Mishel (1988) comprise methods used to maintain hope. The six dimensions of hope maintenance include: 1) downward comparison (alpha .79); 2) fostering optimism (alpha .69); 3) belief in a powerful other (alpha .78); 4) avoiding painful material (alpha .80); 5) situation as temporary (alpha .88); and 6) blaming the victim (alpha .76). Viewing the situation as temporary is the belief that unstable situations are of limited duration. Attributing the cause of complications to the victim's personality or behavior is the definition of blaming the victim. Downward comparison is the evaluation of one's own situation as more advantageous than others. Fostering optimism is achieved by emphasizing a positive view of events. Belief in a powerful other is the reliance on faith in a supreme force. Avoiding painful material consists of the conscious evasion of negative situations.

Each dimension of hope maintenance contains from two to seven items in a Likert format. Items address both the use and degree of success of the hope maintenance method. A total of 27 items comprise the scale.

The Hope Maintenance Scale was used with family members and heart transplant recipients in the study "Predictors of Quality of Life in Heart Transplantation" (Murdaugh &
Mishel, 1988). Although the Hope Maintenance Scale was generated from data obtained from family members of recipients during family support groups, it is unknown whether the items reflect the concerns of heart transplant patients themselves. To determine whether there are other concerns specific to the transplant patients that should be added to the Hope Maintenance Scale, qualitative data gathered from heart transplant recipients in the "Predictors of Quality of Life in Heart Transplantation" study were analyzed. The analysis was performed to determine if the items contained in the scale represent concerns of the patient. Results of the analysis provided information regarding the relevance of the instrument for future use with both recipients and their partners.

**Purpose**

The purpose of this study was to validate the appropriateness of using the Hope Maintenance Scale with heart transplant recipients, and to refine the scale. A content analysis of the qualitative data collected from transplant recipients in the "Predictors of Quality of Life in Heart Transplantation" project (Murdaugh & Mishel, 1988) was conducted to fulfill this objective. Content analysis was used to verify the concerns of recipients and determine if they coincide with those of family members. The scale was broadened to include items that mirror these concerns. Recipients supplied data in the form of written responses to
the statement: "In the following space, please tell us anything you think is important about living with a heart transplant that was not covered in the booklet." Data gathered from these responses were compared to items in the Hope Maintenance Scale. Convergence of the two data sources provided evidence that the scale addresses hope maintenance items which reflect patients' concerns as well as those of family members. Relevancy of the scale for use with both recipients and their family members was therefore established.

**Significance**

Due to the dramatic advances in infection and rejection surveillance and treatment, heart transplantation offers more patients a greater chance at a longer life. The quality of this extended life is of importance equal to that of the rate of survival. Medical complications, medication side effects, financial concerns, and psychosocial adjustments are part of the patient's life after transplant.

Maintenance of hope has been identified as a strategy utilized in coping with the unpredictability of physical and psychological well-being. Coping skills may be enhanced by the use of strategies that build and maintain hope. Quality of life can thereby be enhanced for both recipients and their partners.

The concept of hope as significant to quality of life has relevance for nurses. Nurses take part in the
transplant process as they care for the patient in the hospital, outpatient, and home settings (Irwin, 1987). Nurses have a direct role in assessing physical, as well as psychological well-being. Patient education regarding physical and psychological care and self-care is also a nursing responsibility. Nurses, therefore are in a vital position to facilitate coping by utilizing and teaching strategies to maintain hope.

**Summary**

Quality of life has been identified as a concern for the increasing numbers of heart transplant recipients who survive to experience the unpredictability of physical and psychosocial changes. Maintenance of hope is one variable that enhances adaptation to these changes. The Hope Maintenance Scale was developed from data collected from family members of heart recipients. The scale was refined based on a content analysis of data collected from recipients in the "Predictors of Quality of Life in Heart Transplantation" study. This established validation of the scale as well as relevancy for its future use with both recipients and partners.
CHAPTER 2

Conceptual Framework and Literature Review

The concepts that are addressed in this study were derived from the conceptual framework that formed the basis for the study, "Predictors of Quality of Life in Transplantation" (Murdaugh & Mishel, 1988). Concepts for the primary study were generated from grounded theory and supported by the literature. The concepts consisted of interpersonal and intrapersonal variables theorized to be significant predictors of quality of life in the first six months post-transplant.

For this study, the concepts of unpredictability, hope, and the dimensions of hope are described based on review of the literature. The conceptual framework is presented in Figure 1. A relationship among the concepts is also described as cited in the literature. The psychological distress experienced by patients with chronic illness is potentiated by unpredictability, a component of uncertainty. Various coping strategies are used to reduce psychological distress and to improve adjustment to illness. Hope is suggested as one coping strategy that can be used to enhance well-being. The six dimensions of hope maintenance are utilized to varying degrees toward effective coping. The concepts and their relationships are presented in the following literature review.
Figure 1. Conceptual Framework—Relationship of Unpredictability to Hope Maintenance

HMS = Hope Maintenance Scale
MUIS = Mishel Uncertainty in Illness Scale
MUS = Managing Unpredictability Scale

- Focus of Current Study
Concept Level

Unpredictability

Murdaugh and Mishel (1988) define unpredictability as a "lack of stability in the course of illness or outcome" (p. 46). Unpredictable situations are those that lack "cue-outcome contingency" (p. 46), that is, situations that cannot be anticipated by a specific probability of occurrence. Uncertainty occurs when a situation cannot be predicted and/or when its meaning cannot be assigned (Mishel, 1988). Unpredictability is conceptualized as a component of uncertainty.

Mishel (1981, 1984, 1987, 1988) has provided a theoretical model of uncertainty in illness that has greatly contributed to the nursing literature on this concept. The model provides a theoretical link for examining the relationship of the variables of uncertainty (Yarcheski, 1988). The model contains components that patients draw upon to form a framework or schema from which to assign meaning to illness-related events. Symptom pattern, event familiarity, and event congruence are the components of a schema which can result in reduced uncertainty. Uncertainty occurs when a schema cannot be found (Mishel, 1988).

Uncertainty occurs in four forms in the illness experience: (a) ambiguity regarding the state of illness, (b) complexity regarding the treatment and care systems, (c) lack of information about the diagnosis and seriousness of
the illness, and (d) unpredictability of the course of the disease and prognosis (Mishel, 1988). Increasing the ability to predict, anticipate, or understand an aversive stimuli often reduces distress (Krantz, 1980). If the unpredictability is not controlled, it can mediate one's response to stress. The concept of unpredictability, a component of uncertainty, is of concern in living with heart transplantation.

Mishel and Murdaugh (1987) examined the unpredictability in patients following heart transplantation. Unpredictability was described as unknowns that are present throughout the pre- and post-treatment periods. Both the recipient and the family experience cognitive and behavioral changes, a process termed "redesigning the dream", in an attempt to adjust to living with transplantation. Adjustment to the unpredictability is one variable in redesigning the dream. As an outgrowth of the study, the Managing Unpredictability Scale was developed, using qualitative data collected during the study. The scale measures methods used by family members to cope with the unpredictability of the transplantation experience.

Several studies have explored the influence of uncertainty on coping strategies and psychological distress or adaptation. Christman et al. (1988) used a longitudinal exploratory design to measure the impact of uncertainty in
illness and the use of coping methods on emotional distress and recovery following myocardial infarction. Variables were measured on 70 patients with confirmed myocardial infarction at three times during the recovery period; prior to hospital discharge, 1 week following discharge, and 4 weeks after discharge. The Mishel Uncertainty in Illness Scale was used as the measure of uncertainty; the Profile of Mood States was used to measure emotional distress; and the Jalowiec Coping Scale was used to measure coping methods. From the results, the authors concluded that high levels of uncertainty were directly related to high levels of emotional distress in the pre- and post-discharge recovery periods. An increase in coping strategies to decrease emotional distress induced by uncertainty emerged only after hospital discharge. This suggests that the hospital environment may limit the patient's coping behavior in a way that inhibits the use of coping measures that allow for the expression of feelings.

In a related study, Webster and Christman (1988) conducted a descriptive survey of 20 patients with confirmed myocardial infarction to identify the relationship between perceived uncertainty and coping methods used in adapting to the illness. Uncertainty was measured by the Mishel Uncertainty in Illness Scale; coping strategies were measured using the Jalowiec Coping Scale. Study results suggest that when faced with uncertainty, patients with
myocardial infarction respond to the emotional distress by using coping strategies. Emotional distress as a result of uncertainty was reported to continue after hospital discharge.

A path model illustrating the relationship of uncertainty to adaptation was developed by Wineman (1990) using a convenience sample of 118 multiple sclerosis patients. The author indicated that in addition to other variables, such as social support and functional disability, uncertainty had a direct effect on adaptation.

A review of the literature of unpredictability, a component of uncertainty, in several patient populations indicates a relationship between uncertainty and psychological distress and problems in adaptation. Research presented examined patients with some form of chronic illness. Because heart transplantation is also a long-term process these research findings pertain to this patient population, as well.

Hope

Hope is defined by Stotland (1969) as an expectation greater than zero of achieving a goal. Hopefulness is necessary for action or motivation to achieve a goal. Motivation is a function of the perceived probability of achieving the goal and the perceived importance of the goal. Therefore, increased expectation of goal attainment and increased importance of the goal leads to more thought about
how to attain the goal (Stotland, 1969). Smith (1983) stated that hope facilitates coping in ways that make desirable outcomes possible.

The process of hoping has a strong relationship to physical and emotional well-being (Adams & Proulx, 1975). Dugan (1987-88) proposed that a sense of hope can be a source of strength to cope with events that might otherwise be mentally and emotionally overwhelming. McGee (1984) stated that hope strengthens the physiological and psychological defenses in illness-related events.

The loss of hope, referred to as hopelessness or despair, has been documented (Boyajean, 1979; Isani, 1963; Vaillot, 1970) as giving up or losing motivation. Its effects can be manifested in refusal of food and social interaction, feelings of helplessness, weariness, or fear (Dufault & Martocchio, 1985). Nardini (1952) documented many instances in American POW's of World War II in which feelings of helplessness were followed by death not attributed to physiologic causes.

The influence of hope has been investigated in specific patient populations. Examination of hope in cancer has been extensive, but the concept has also been studied in psychiatric disorders, multiple sclerosis, and heart disease.

Dufault and Martocchio (1985) described dimensions of hope based upon clinical data collected over a two-year
period on 35 elderly cancer patients. The dimensions of effective, cognitive, behavioral, affiliative, temporal, and contextual were described. Suggestions for the role of nurses in supporting and facilitating patients' hope within each dimension were included.

Hinds (1984, 1988) used grounded theory methodology to propose a definition of hope in adolescents, as the degree of reality-based, life-sustaining belief that a positive future exists for self and others. Data were collected by interviews and observations of interactions of three groups of adolescents with health care personnel and family members over a two-year period. The first group, a convenience sample, consisted of 17 well adolescents. The second group consisted of 42 adolescents who were inpatients in a substance abuse treatment unit. The third group consisted of 58 adolescents who were inpatients or outpatients with various diagnoses and stages of cancer. Four dimensions of the adolescents' hopefulness were described as (1) forced effort, the degree to which an adolescent tries to artificially take on a more positive view, (2) personal possibilities, the extent to which an adolescent believes that second chances for the self may exist, (3) expectations of a better tomorrow, the degree to which an adolescent has a positive although nonspecific future orientation, and (4) anticipation of a personal future, the extent to which an adolescent identifies specific and positive future
possibilities for self. Adolescents' hopefulness had a focus on self and concern for their personal futures, but a theoretical sampling of the cancer group revealed the additional attribute of concern for and focus on others. Another finding revealed was that as the level of hopefulness increased, a concomitant increase in specificity of hoped-for objects occurred.

In a follow-up study, Hinds and Martin (1988) collected qualitative data from 58 adolescents with various diagnoses and stages of cancer to identify effective and preferred strategies to achieve hopefulness and competence. Four sequential phases comprised a process of self-sustained hopefulness. The first phase, cognitive discomfort, was defined as the extent to which the adolescent experienced mental uneasiness secondary to negative or disheartening thoughts, and a desire to be relieved of the uneasiness. Distraction, the second phase, was stimulated in order to replace the disturbing thoughts with more acceptable ones. Cognitive comfort, the third phase, represented a desirable state for the adolescents. It was the experience of solace and lifted spirits at times during the illness process. Hopefulness and forgetting cancer were stages used during this phase. The fourth phase that emerged was personal competence. This was the extent to which adolescents perceive themselves as resilient, resourceful, and adaptable when faced with serious health threats. The authors suggest
that research is needed to determine the applicability of these phases to adult cancer patients.

Herth (1989) investigated the relationship between hope and coping in a nonrandom convenience sample of 120 adult patients receiving cancer chemotherapy. The Herth Hoping Scale was used to measure hope and the Jalowiec Coping Scale was used to measure degree of use of coping methods. Findings indicated that when the level of hope was high, the level of coping response was also high, and vice versa. The ability to maintain family role responsibilities was also identified as a significant influence on levels of hope and coping.

Families' views on helpful nursing intervention for cancer patients were examined by Lewandowski and Jones (1988). Nursing interventions that enhanced hope for the patient and for the family were highly rated in the initial phases of cancer. These interventions were rated as less helpful in the terminal and adaptation phases of cancer. The authors speculate that because maintaining hope requires an investment of energy, little energy is available in the later stages of cancer. The sampling method used was a weakness of the study that may decrease the validity of the results. Questionnaires were completed by 62 subjects whose names were drawn from a telephone directory. Subjects were supplied with one of three possible vignettes that could apply to a family member with cancer. Keeping the vignette
in mind, subjects responded to items on the questionnaire. Of the 62 subjects, 40 stated that they had experienced a family situation similar to the vignette they had responded to.

Stoner and Keampfer (1985) examined the relationships of information on life expectancy and phase of illness to levels of hope in a convenience, nonprobability sample of 55 cancer patients. The Stoner Hope Scale was used to measure levels of hope. The Beck Hopelessness Scale was used as a criterion measure in order to evaluate the validity of the Stoner Hope Scale. Results indicated higher levels of hope in cancer patients who had no recall of receiving information about their life expectancy, than in those patients who recalled receiving information. There was no difference in level of hope between terminally ill cancer patients and those at other phases of illness.

The relationship between feelings of hope, emotional discomforts, and the motivation to seek follow-up care was investigated in 27 patients seeking psychiatric help in the emergency room of a large city hospital (Perley, Winget, & Placci, 1971). The psychiatric Morbidity Scale was used to rate the degree of patients' psychiatric signs and symptoms, and a 5 minute verbal sample was utilized to elicit responses about interesting personal life experiences. The Hope Scale was used to score the 5 minute verbal sample. Findings indicated that those patients who followed through
on recommended treatment had higher levels of hope. The authors posited that the decision to seek treatment is made if the patient feels hopeful that symptoms can be relieved.

A descriptive study was conducted by Foote, Piazz, Holcombe, Paul, and Daffin (1990) to determine if a relationship exists between the variables of hope, self-esteem, and social support in 40 multiple sclerosis patients. The Miller Hope Scale, the Rosenberg Self-Esteem Scale, and the Personal Resources Questionnaire were used to measure the variables. Results revealed a positive relationship among all three variables.

Finally, a descriptive study of hope was conducted by Rideout and Montemuro (1986) to examine the influence of physiological status and function on hope, morale, and social function. The convenience sample consisted of 23 patients with chronic heart failure. The Beck Hopelessness Scale and the Philadelphia Geriatric Centre Morale Scale were used to measure hope and morale. The physical and social functioning were measured with the McMaster Health Index Questionnaire. Hope, morale, and social functioning were correlated but physical functioning did not have a significant relationship to hope, morale, or social functioning. This suggests that patients who are more hopeful maintain their involvement in life regardless of physical limitations imposed by heart failure.
This research supports the concept of hope as having a positive influence on adaptation and coping to illness-related events. The literature focuses on hope in chronic illness. Because heart transplantation is also a long-term illness process, the concept of maintaining hope has relevance for these patients, as well. Hickey (1986) stated that hope is a wonderful dimension of life that enables the living to continue living and the dying to die more easily.

**Dimensions of Hope**

Six dimensions of hope maintenance have been identified by Murdaugh and Mishel (1988); (1) downward comparison, (2) fostering optimism, (3) belief in a powerful other, (4) avoiding painful material, (5) viewing the situation as temporary, and (6) blaming the victim. These are strategies which enable the individual to remain hopeful. The literature supporting the dimensions is presented.

The dimension of downward comparison was supported by Wills (1981). The author described downward comparison as a method of self-enhancement by the comparison with a less fortunate other. In this way, persons can increase their subjective well-being in situations in which frustration or misfortune has occurred. Hinds (1988) stated that comparing the present situation with other possible outcomes can also enhance well-being. Taylor, Wood, and Lichtman (1983) termed this dimension "selective evaluation" and described
some additional strategies for self-enhancement. Selectively focusing on attributes that make one appear advantaged, identifying benefit from a victimizing event, and fabricating normative standards of adjustment that make one's own adjustment appear exceptional are strategies described.

Fostering optimism, a dimension of the Hope Maintenance Scale, was supported by McGee (1984) as long as the optimism is reality-based. Those who hold unrealistically high levels of hope may be overwhelmed when experiencing crises. A realistic level of optimism can direct energy toward coping with crises (McGee, 1984).

Belief in a powerful other, a third dimension of the Hope Maintenance Scale, was widely supported in the literature as a contributor to hope. Dugan (1987-1988) stated that sometimes hope means choosing to trust in the meaning and purpose of events in the face of uncertainty and without the power to change the course of these events. One way to strengthen hope is to provide a "sense of meaning and purpose to the human spirit" (p. 110). Peck (1981) acknowledged the effect of faith as a curative (or destructive) force in people, whether it is faith in a powerful other or simply faith in the treatment of their illness. Carson, Soeken, Shanty, and Terry (1990) found that in patients with acquired immunodeficiency syndrome, existential and religious well-being were significant
predictors of hope. Women with breast cancer also perceived religious beliefs to be of great help in coping with illness (Brandt, 1987). Finally, Herth (1989) described the positive relationship between religious conviction and hope and coping responses in patients receiving cancer chemotherapy. Patients who possessed a strong religious faith had a higher level of hope and a higher level of coping response than those who had a weak faith or were without faith.

Avoiding painful material or situations, a fourth dimension of the Hope Maintenance Scale, is another strategy to maintain hope. Permitting the individual to psychologically bypass an unpleasant or stressful situation is cited as a key function of hope (Korner, 1970). Hinds (1988) described ways in which adolescents coped with cognitive discomfort, that is, negative or disheartening thoughts. Distraction was used to promote concentration on neutral or positive thoughts and conditions. Another behavior used to avoid disturbing thoughts was to keep busy with physical activity to occupy time and thoughts to provide mental relief.

Blaming the victim, the fifth dimension of hope maintenance, is supported by Janis and Rodin (1979) as a method of assigning causality. To maintain the belief that misfortune or illness do not occur uncontrollably and at random, one attributes cause to the victim. This allows for
the perception of control over the environment. Individuals protect themselves from blame by believing that the victim deserved the misfortune. If the victim is to blame for the unfortunate event, then it can be avoided by others.

Viewing the situation as temporary, the sixth dimension of the Hope Maintenance Scale, is a strategy that is used by adolescents to maintain hope (Hinds, 1988). Adolescents reported looking forward to normalcy in the future. This strategy projects the patient into the future of improved or recovered health.

In summary, the dimensions of hope maintenance described by Murdaugh and Mishel (1988) are supported in the literature. These strategies are utilized to enhance coping with a stressful event or illness.

A review of the literature on unpredictability and hope has been presented. A relationship between the two concepts must now be explored to provide linkage to transplant patients and their adjustment to the transplantation process.

The relationships among uncertainty, hope, and psychosocial adjustment were examined in 55 patients receiving radiotherapy for cancer (Christman, 1990). The Mishel Uncertainty in Illness Scale was used as the measure of uncertainty; the Beck Hopelessness Scale was the indicator of hope; and adjustment was measured with the Psychosocial Adjustment to Illness Scale. Greater
uncertainty and less hope were reported as associated with and predictive of psychosocial adjustment problems. The relationship of uncertainty and hope was described as negative, that is, as patients experienced more uncertainty they also experienced less hope.

These results were consistent with the findings of Mishel et al. (1984) in 54 women receiving initial treatment for gynecological cancer. The influence of uncertainty and optimism upon psychological adjustment was examined. The Mishel Uncertainty in Illness Scale was used to measure uncertainty, the Beck Hopelessness Scale measured optimism, and the Psychological Adjustment to Illness Scale was used as the measure of adjustment. Those women who experienced more uncertainty, had significantly less optimism about their situation and more adjustment difficulties. Thus, it was concluded that uncertainty may be detrimental to keeping the patient hopeful.

In studying children undergoing bone marrow transplantation, Artinian (1984) described the value of professional helping relationships in assisting the children and their parents to experience mutual supportive relationships. The importance of fostering hope to enhance coping with the pain, isolation, and unpredictability of the transplant process was emphasized. A model for fostering hope was proposed as a way to reduce some of the demands on physical and emotional resources.
Finally, in another study, grounded theory methodology was used to examine the concerns of 14 patients awaiting kidney transplantation (Weems & Patterson, 1989). One theme that emerged was the concept of uncertainty during the waiting period. Patients viewed feelings of hopefulness as a way to cope with the uncertainty.

**Summary**

The concepts of unpredictability and hope maintenance have been presented, and their relationships have been supported by the literature. Hope is supported as a strategy to cope with unpredictability, thereby influencing psychological adjustment to illness. The concepts are prevalent in heart transplantation and other chronic illnesses. Successful strategies of maintaining hope can enhance adaptation of recipients and their families to transplantation.
CHAPTER 3
Research Methodology

In this chapter, a description of the design, sample, human subjects considerations, method of data collection, and data analysis protocol of "Predictors of Quality of Life in Heart Transplantation" (Murdaugh & Mishel, 1988), the primary study, is provided. The research methodology of the secondary study is presented as well.

Primary Study

Design

The purpose of the primary study was to test the Quality of Life in Organ Transplantation Model (NCNR Grant #1-86-6004791-B8, 1988), using causal modeling methodology. Causal modeling enabled the researchers to utilize descriptive data to explain phenomena. The nursing model, generated from grounded theory and literature support, is comprised of variables theorized to be significant interpersonal and intrapersonal predictors of quality of life following organ transplantation. Qualitative data used in the development of the model were obtained from interviews with family members of heart transplant patients. Predictors of quality of life and the relationships among the concepts were described in the model, which was tested in the primary study to identify concepts described by both family members and recipients as predictive of quality of life.
Sample

The sample included heart transplant recipients and an equal number of partners from transplantation programs throughout the United States. The total number of subjects was 305. Partner refers to persons identified by the recipient as a significant other living in the same household (i.e., spouse, parent, partner, or friend). The following criteria were used for subject selection:

1. Heart transplant recipient,
2. Eighteen years old or older,
3. Willing and able to identify a significant other,
4. Person identified by recipient as significant other.

Protection of Human Subjects

Data collected from patients and partners were used exclusively for research purposes. Subjects voluntarily agreed to participate in the study with the understanding that withdrawal from the study would not affect care in any way. This information was provided in a disclaimer sent to each subject. Human subjects approval was granted by the institutional review board of the University of Arizona College of Nursing. There were minimal or no risks to subjects. Anonymity was preserved by assigning subjects code numbers. Confidentiality was ensured by storing the master list of subjects in a locked file in the office of the principal investigator.
Data Collection Protocol

A letter requesting participation in the study was sent to each potential subject, along with a request for the name and address of the person designated as the partner. A mail survey was then sent to subjects who agreed to participate in the form of a test booklet which contained eight questionnaires. The booklet was accompanied by a letter of explanation and a stamped, addressed return envelope. Subjects who did not respond received a new copy of the questionnaire booklet and a telephone follow-up.

Instruments

The test booklet contained eight scales: Nottingham Health Profile, Unpredictability Scale, Unpredictability Management Scale, Hope Maintenance Scale, Perception of Future Scale, Mental Health Inventory, Life Satisfaction Self-Anchoring Scale, and a Demographic Data Form. The patient completed all scales; the partner completed all scales except the Nottingham Health Profile. In addition to data collected with the questionnaires, a research assistant travelled to each clinical site to obtain objective data from recipients' medical records, for which permission was granted.

The questionnaires were contained in a 15 page booklet. The entire last page was blank in order to collect written responses to the open-ended question, "In the following space, please tell us anything you think is important about
living with a heart transplant that was not covered in the booklet."

**Secondary Study**

**Design**

An exploratory descriptive design was used to analyze data obtained from the primary study. Content analysis was performed on the qualitative data collected in the form of written responses to the open-ended statement on the final page of the test booklet. The objectives of the analysis were to support items contained in the Hope Maintenance Scale and to expand the scale to include items that reflect concerns unique to the transplant recipient.

**Sample**

The sample consisted of 226 subjects drawn from the 305 participants in the original study. The subjects from whom data were determined as ineligible for this study did not have a corresponding partner who also participated.

**Protection of Human Subjects**

Anonymity and confidentiality were ensured by the number coding of all transcriptions. Approval for the study was granted by the University of Arizona Human Subjects Committee (Appendix A).

**Data Analysis Plan**

Content analysis was the method used to assess data in order to lend support to items contained in the Hope Maintenance Scale. It was also possible to broaden the
domain of the scale to include items which emerged from the data that reflect specific concerns of transplant recipients.

Content analysis is a research method used to analyze verbal, written, or visual communication messages to discover, expand, and test knowledge (Cole, 1988). When applied to data collected in clinical settings, content analysis is a relevant strategy for conducting practice-oriented nursing research. It is valuable in evaluating whether the concepts under study and the items that measure the concepts are linked appropriately and logically (Dempsey & Dempsey, 1986). Qualitative data enrich and extend the definitions and aspects of a concept most often cited in the literature (Tilden, Nelson, & May, 1990). The use of preexisting available data allows comparisons and contrasts to be made between past study results and current study results (Dempsey & Dempsey, 1986). The use of previously produced data also minimizes the effect of communicator bias (Cole, 1988).

Content analysis involves the systematic and objective reduction of recorded data to a set of categories for purposes of classification, summarization, and tabulation (Fox, 1982). Inferences were made by identifying specific characteristics of the message (Holsti, 1968). With this method, verbal and behavioral responses can be used to answer questions relevant to nursing (Waltz, Strickland, &
Verbal responses such as those generated by open-ended questions, lend themselves to content analysis methodology. Responses to open-ended statements are based on subjects' most recent experiences and thereby provide a very rich data source that gives an understanding of the subjects' social world (Knafl & Howard, 1986). Content analysis is often necessary when the subjects' own language is crucial to the research problem (Holsti, 1968). Careful analysis of the content of the responses can reveal a great deal about the subject that might be lost if closed or structured measuring instruments are used (Dempsey & Dempsey, 1986). A broad range of social and psychological concepts, such as attitudes, needs, perceptions, and values, can be measured using content analysis (Polit & Hungler, 1989).

Content analysis includes three basic steps: 1) selecting the units of analysis, 2) developing a category system for classifying units of content, and 3) developing explicit coding rules (Waltz, Strickland, & Lenz, 1984). The entire written text of each subject was examined, however, phrases and sentences were the unit of analysis since they are more complex and impart more meaning than words taken individually (Waltz, Strickland, & Lenz, 1984). Groups of words acted as indicators of concepts or characteristics to guide categorizing. Phrases or sentences
which represent similar topics or ideas were clustered together into categories (McCain, 1988).

The category system that was used to classify units of content were the six dimensions of hope maintenance described by Murdaugh and Mishel in the primary study (1988). In addition, content not reflecting the six dimensions were used to identify new categories. The categories were derived inductively from the themes that emerged from the content representing other hope maintenance strategies. These categories were used to develop additional items of the Hope Maintenance Scale.

The analysis to identify new thematic categories was done both at the manifest level and the latent level (Fox, 1982). At the manifest level, what the respondent said or wrote was analyzed without making assumptions about the content. At the latent level, responses were analyzed in terms of the meaning of the response. Content and meanings were then grouped into categories according to their similarities or differences (Swanson, 1986). While coding and analyzing, the researcher looked for patterns or recurrent themes or meaningful units that represented the subjects' major ideas (Hutchinson, 1986). Incidents of a particular characteristic were compared to other incidents. Incidents were then compared with categories, which were then compared to other categories. In this way, similarities and differences of characteristics were
distinguished and the basic properties of each category were defined. Differences established boundaries; similarities clarified relationships. The researcher defined a category by searching for its structure, cause, content, dimensions, consequences, and relationships to other categories (Hutchinson, 1986).

Several coding rules guided the placement of groups of words or sentences into specific categories. First, immersion in the data was necessary to classify data bits. Data were read repeatedly until themes emerged. Each transcript reading revealed insight into characteristics that could be clustered into categories of hope maintenance dimensions. Following a method described by McCain (1988), the main topic of each phrase or sentence was written in the margin of the transcript sheets. This method of coding is referred to as open coding (Hutchinson, 1986). Code words were assigned to each phrase or sentence to ensure "full theoretical coverage" (p. 136). Some of the code words comprised categories and some code words were combined to form categories.

A second coding rule was that the themes must have theoretical links to the concept of hope maintenance. The six dimensions of hope maintenance comprised the categories into which the data bits were clustered. Additional categories were constructed as new hope maintenance strategies emerged as described by subjects. Categories
needed to be sufficiently detailed and mutually exclusive so that all phrases or sentences could be coded (Fox, 1982).

Third, interrater reliability was set at 80% before a theme could be grouped into categories. Definitions of hope maintenance strategies from the primary study were used to guide categorizing. New categories derived from the data from this study were defined and discussed in a group review. An investigator from the primary study reviewed categories in order to validate placement of the themes. The investigator's experience with the concept of hope maintenance provided a background from which to interpret data (Corbin, 1986).

**Summary**

Research methodology for the primary and secondary studies have been described. Content analysis was selected as the method to analyze data from the larger study (Murdaugh & Mishel, 1988). Steps and coding rules of content analysis were presented. Data were grouped into categories representing the dimensions of hope maintenance, in the attempt to support and broaden items that comprise the Hope Maintenance Scale.
CHAPTER 4

Results

In this chapter, the results of the data analysis are presented. Characteristics of the sample are described, followed by a discussion of the original hope maintenance categories which were found in the qualitative data of the patients' responses. Finally, new categories that represent other strategies used to maintain hope, are presented.

Characteristics of the Sample

Of the 305 participants in the primary study, "Predictors of Quality of Life in Heart Transplantation", 226 (74%) were transplant recipients who responded to the open-ended statement at the end of the questionnaire booklet. These respondents had partners who also responded to the questionnaire. The demographic data in Tables 1 and 2 describes the 305 subjects in the primary study. The sample consisted of 226 (74%) males and 79 (25.9%) females. A total of 104 (34%) subjects were employed either full or part-time. Over one half (N=174, 54%) of the participants had college or graduate credits. Yearly income of $30,000 or less was reported by more than one half (N=179, 59%) of the sample. Age of participants ranged from 18-68 years, with a mean of 49.2 (sd=11.1 years). Years since transplant ranged from 1-17 years, with a mean of 3.5 (sd=2.2 years). Finally, subjects reported being ill before transplant a
mean of 4.1 years (sd=5.1 years). Years of illness
pre-transplant ranged from 1-41 years.
Table 1.

PREDICTORS OF QUALITY OF LIFE IN HEART TRANSPLANTATION
Categorical Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency (n=305)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>226</td>
<td>74.1</td>
</tr>
<tr>
<td>Female</td>
<td>79</td>
<td>25.9</td>
</tr>
<tr>
<td>Total</td>
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<tr>
<td><strong>Educational Level</strong></td>
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<tr>
<td>Grade School</td>
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</tr>
<tr>
<td>Some High School</td>
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<td>11.1</td>
</tr>
<tr>
<td>High School</td>
<td>87</td>
<td>28.5</td>
</tr>
<tr>
<td>Some College</td>
<td>87</td>
<td>28.5</td>
</tr>
<tr>
<td>College Degree</td>
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</tr>
<tr>
<td>Post-Grad. Credit</td>
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<td>4.6</td>
</tr>
<tr>
<td>Post-Grad. Degree</td>
<td>27</td>
<td>8.9</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>Total</td>
<td>305</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
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<td></td>
</tr>
<tr>
<td>Work full time</td>
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<td>23</td>
</tr>
<tr>
<td>Work part time</td>
<td>33</td>
<td>11</td>
</tr>
<tr>
<td>Homemaker</td>
<td>47</td>
<td>15</td>
</tr>
<tr>
<td>Retired pre-op</td>
<td>74</td>
<td>24</td>
</tr>
<tr>
<td>Retired post-op</td>
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<td>16</td>
</tr>
<tr>
<td>Missing</td>
<td>32</td>
<td>11</td>
</tr>
<tr>
<td>Total</td>
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<td>100</td>
</tr>
<tr>
<td><strong>Yearly Family Income</strong></td>
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</tr>
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<td>Under $10,000</td>
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<td>12.1</td>
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<td>$10,000-20,000</td>
<td>75</td>
<td>24.6</td>
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<td>$21,000-30,000</td>
<td>67</td>
<td>22.0</td>
</tr>
<tr>
<td>$31,000-40,000</td>
<td>39</td>
<td>12.8</td>
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<td>$41,000-50,000</td>
<td>17</td>
<td>5.6</td>
</tr>
<tr>
<td>Above $50,000</td>
<td>59</td>
<td>19.3</td>
</tr>
<tr>
<td>Missing</td>
<td>11</td>
<td>3.6</td>
</tr>
<tr>
<td>Total</td>
<td>305</td>
<td>100</td>
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</tbody>
</table>
Table 2.  
PREDICTORS OF QUALITY OF LIFE IN HEART TRANSPLANTATION  
Demographic Data

<table>
<thead>
<tr>
<th>Variable</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>49.2 (sd= 11.1 yrs)</td>
</tr>
<tr>
<td>Mode</td>
<td>56.0</td>
</tr>
<tr>
<td>Range</td>
<td>18-68</td>
</tr>
<tr>
<td><strong>Number of Children</strong></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>2.9 (sd= 1.6)</td>
</tr>
<tr>
<td><strong>Years Since Transplant</strong></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>3.5 (sd= 2.2 yrs)</td>
</tr>
<tr>
<td>Mode</td>
<td>2.0</td>
</tr>
<tr>
<td>Range</td>
<td>1-17</td>
</tr>
<tr>
<td><strong>Time Ill Pre-Transplant</strong></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>4.1 yrs (sd= 5.1 yrs)</td>
</tr>
<tr>
<td>Range</td>
<td>1 month- 43 yrs</td>
</tr>
</tbody>
</table>
Categories Supporting Dimensions of Hope Maintenance

The purpose of the study was to identify strategies used by transplant recipients to maintain hope and to determine whether these strategies matched those in the Hope Maintenance Scale. Hope maintenance is defined by Murdaugh and Mishel as "the cognitive appraisal of transplant-related events so that a positive evaluation emerges" (1988, p. 40). Content analysis was performed on qualitative data which were collected in the form of written responses to the statement, "In the following space, please tell us anything you think is important about living with a heart transplant that was not covered in the booklet". The data were examined for the six themes which reflected strategies used to maintain hope identified in the primary study: 1) Downward Comparison, 2) Fostering Optimism, 3) Belief in a Powerful Other, 4) Avoiding Painful Material or Situations, 5) Viewing the Situation as Temporary, and 6) Blaming the Victim.

Five of the dimensions of hope maintenance were supported by the qualitative data analyzed in the study. Blaming the Victim was a strategy that was not expressed by the respondents.

Repeated review of the data confirmed the categories that emerged supporting five of the hope maintenance dimensions. Subcategories were also generated for some of the categories. A new variable, Normalizing, was identified
and proposed as an antecedent of hope. These categories were then reviewed for agreement by an investigator from the primary study. Each category and its subcategories is described and sample statements that exemplify the theme are included. Appendix B contains all statements from the data that were categorized within the dimensions of hope.

Dimensions of Hope Maintenance

Downward Comparison

Murdaugh and Mishel (1988) described Downward Comparison as the evaluation of one's own situation as more advantageous than others. Comparing the present situation with other possible outcomes, that is, a feeling that 'it could be worse', is another form of Downward Comparison (Hinds, 1988). The four statements presented are an example of the 14 statements found in the data, which represent the theme of Downward Comparison.

1006:Living with a heart transplant isn't always smooth sailing; but it's better to be than not to be.
3012:Within the group I'm the longest surviving transplant...
3019:I strongly feel most would have gave up. But I didn't.
7065:My quality of life is not as it was before my sickness but it is a lot better than some of the transplants I have met.

Subcategory: Exceptional Experience
A subcategory of Downward Comparison emerged from the data and was termed Exceptional Experience. This was a feeling expressed that the transplant recipient's experience was unlike those who have not had a transplant. A total of 5 statements reflected the category of Exceptional Experience. The following are examples of these statements.

3072: There is a spirit to life that can't be explained to anyone who has not been sentenced to death and come home free.
4018: Only we understand what the experience is like.
7050: You can never know the full extent of it till you have had a transplant, cause no one can tell you or explain what you're going through. Only those of us who have had it know the full meaning.

**Fostering Optimism**

The category, Fostering Optimism, represents the strategy described as the emphasis on a positive view of events (Murdaugh & Mishel, 1988). The following responses were found to reflect optimism.

1016: I'm the same person I was only with a better outlook on life!
1001: I am a positive thinker and refuse to accept a short future.
3173: The best way to get along with a transplant is to keep a positive attitude about everything. I have my good days and bad days as far as physical activity but
with a positive attitude things go a lot better. I think a positive outlook has a lot to do with a successful transplant.

8048: Always think positive.

These statements supported the dimension of Fostering Optimism. There were 51 such statements of optimism. In addition, four subcategories of optimism emerged as: Forced Optimism, Guarded Optimism, Euphoria, and Gratefulness. The subcategories indicate varying levels of optimism. A description of the subcategories along with representative statements is presented.

Subcategory: Forced Optimism

The subcategory of Forced Optimism reflects optimism expressed with a negative tone. The following statements illustrate this view.

1009: Of course the main thing is I'm alive. However, I am very able to return to work, but no major company as my past employer will take me back, because I cannot be covered by insurance, "OF ANY KIND".

3150: I am thankful to be alive, but living with the constant unknown future, complications and medications is hard.

3009: I concentrate on my good days and what I can do but am always fearful when things are not going well...I am hopeful but when things do not go well, it
is very stressful and it gets harder and harder to be positive.

7030: Biological survival is important, and for me, it's working well. However, it appears that it will ultimately lead to financial ruin. That's when it becomes difficult to live with a transplant.

Statements of Forced Optimism emphasize the recipients' struggle to remain optimistic in the face of overwhelming difficulties. There were 21 statements which described feelings of Forced Optimism, a level of optimism.

Subcategory: Guarded Optimism

Guarded Optimism is a subcategory of optimism which is expressed at a more positive level. The tone of these statements is that of a reality-based optimism. The following statements exemplify Guarded Optimism.

3153: Lack of sleep—just so many problems— but I'm a very fortunate man and I do enjoy living and look forward to every day.

3032: That he has up and downs will never be 100% but will have a full life with proper adjustments.

3140: The "good" days outnumber the "bad" days.

3100: What is important is to recognize that life can be good, maybe not the same as it was, yet still good.

4040: You still have to take chances.
Statements such as those above were expressed by 31 subjects. Guarded Optimism indicates a more positive level of optimism maintained by transplant recipients in light of difficulties experienced.

Subcategory: **Euphoria**

Euphoria is a subcategory which represents an extremely positive level of optimism. Optimism in this category is not qualified by attention to difficulties experienced. Optimism is expressed as a joy for living. Examples of Euphoria which emerged from the data are as follows:

3019: I celebrated my four year anniversary. I feel real great, everything is going real well.

4008: To enjoy each day as it comes and not to worry about tomorrow! To take joy and pleasure in those things around me such as my children...

4012: Getting out of bed in the morning is special. Every once in a while I pull off the shelf a book that's been waiting for a long time, crack it open, and realize: I almost didn't get to read this one.

There were a total of 28 similar statements reflecting Euphoria. This seemed to be the highest level of optimism.

Subcategory: **Gratefulness**

The theme of gratefulness was a level of optimism which seemed to represent feelings of indebtedness and thankfulness. Some patients expressed the transplant as a
privilege given to them by others. Statements which reflect the recipients feelings of gratefulness are as follows:

3054: 
...just be thankful someone was good enough to be a donor.

3140: I am very happy and grateful to have been given the opportunity for a transplant.

5151: 
...I am happy to be living and thankful to everyone who helped me.

7047: I'm most fortunate to have a new chance at life and I thank everyone.

Belief in a Powerful Other

The dimension of Belief in a Powerful Other is described by Murdaugh and Mishel (1988) as the reliance on faith in a supreme force. The data contained 30 statements which expressed faith in spiritual beliefs. The following are examples of these:

3185: 
...with my will and God's blessings, the sky's the limit.

3147: I found in my situation hope is my best friend along with faith.

4048: I prayed a lot and just always thought the Lord would take care of me.

8060: My faith in God, and the power of prayer have played a great part in my life before and since my transplant.

Avoiding Painful Material or Situations
Avoiding Painful Material or Situations is a dimension of hope maintenance that was supported by the data. This dimension consists of evasion of negative situations to enhance hopefulness (Murdaugh & Mishel, 1988). Of the 6 statements that emerged which represent this dimension, four are included:

3125: I try very hard to stay away from other transplant patients.
3160: Keep out of all stressful situations.
3124: I do not associate with other transplant patients.
6039: Do not dwell on what happened to you.

**Situation as Temporary**

Viewing the Situation as Temporary is described as the belief that unstable situations are of limited duration (Murdaugh & Mishel, 1988). This was not a predominant concept expressed in the data. However, two statements did reveal the use of this strategy:

3183: I know things could be better and that is what I look forward to when I had the transplant.
5042: I have hope that maybe someday things may get a little better.

**Blaming the Victim**

The dimension of Blaming the Victim is defined as attributing the cause of complications to the victim's personality or behavior (Murdaugh & Mishel, 1988). The data
did not contain any statements which would support this dimension of hope maintenance.

**Normalizing**

Normalizing was a new category which emerged from the data and appeared to enhance recipients' adjustment to living with transplantation. Olson (1985) defined normalizing as the establishment of patterns of everyday life which are as close as possible to societal norms. The phrase 'as close as possible' allows for individual considerations. This can be applied to the unique transplant experience. Normalizing consists of acknowledging the impairment but defining life as essentially normal (Knafl & Deatrick, 1986).

Deatrick, Knafl, and Walsh (1988) explored behavioral strategies used by parents of ill children to normalize their child's and family life. Parents described the work of normalization as a constant process of accommodation to the changing physical and emotional needs of the child. Gibson (1988) examined perceived coping of parents of children with cystic fibrosis. While parents did not perceive the disease as normal, their efforts to manage the illness and other aspects of family life was perceived as normal. Actions directed toward managing the treatment regimen and maintaining family stability were positive coping behaviors for the parents in the study. Tack and Gilliss (1990) explored the strategy of normalizing in 75
cardiac surgery patients. Patients resumed or found activities that made them feel as if they were 'back to normal' following surgery.

The purpose of using strategies of normalizing is to enhance the perception of the future as positive (Holaday, 1984). If difficulties of the illness are minimized, expectations for the future can become similar to others' expectations. As a result of a positive outlook on the future, hopefulness may exist. Therefore, as a result of this study, normalizing is proposed as an antecedent of hope maintenance strategies. Statements which expressed the use of Normalizing, were present in this study's data. Of the 38 subjects who described normalizing activities, 23 (61%) also used other hope maintenance strategies. Euphoria, a highly positive subcategory of optimism, was expressed by 5 (13%) of these subjects. The following statements are examples of Normalizing:

3085: Accept the donor heart as my own and get back to normal life. Don't live with pity and try not to let your family spoil you and make you selfish.
3030: ...I seldom think about it and live a normal life within the physical limitations caused by the medications.
5067: I think it's important to have an interest in everyday things of life and to enjoy doing crafts, exercise, etc.
Problems are not different from those encountered by everyone else. Diet and exercise require some discipline and are important. Avoiding sources of infection (within reason) and taking medications as prescribed are the only differences in lifestyle I can see.

There were 38 such statements which exhibited the use of normalizing activities. There were also responses which reflected negative contributors, or threats, to normalizing. Threats are described as events which may potentially impede normalizing (Deatrick, Knafl, & Walsh, 1988). Threats serve as an impetus to alter behavioral strategies in order to maintain normalization.

In this study, there were 26 subjects who described Threats to Normalizing. Nearly half (N=11, 42%) of these subjects used no other hope maintenance strategies. None of the 26 respondents used Euphoria. Forced Optimism, a relatively negative degree of optimism, was used by 4 (15%) of those expressing Threats to Normalizing. Statements from this study which exemplify Threats to Normalizing include:

1012: The worse things about living with a heart transplant are all the medications I have to take and the constant trips to the hospital for follow-up care and biopsy check-up.
I do not take drugs and/or medications well. I never even used aspirin prior to my heart problems. All these drugs really have profound effects on me.

It is very difficult to live with the uncertainty of knowing what the results of the next biopsy may mean that you may die.

There is always problems cropping up, whether they are big or small.

The data contained 26 responses which referred to threats to normalizing. An adjustment in the patient's behavior would be required to accommodate the threats and still maintain the perception of their life as essentially normal (Deatrick, Kanfl, & Walsh, 1988).

**Additional Findings**

Five dimensions of Hope Maintenance Scale were supported by the data in this study. Dimensions of Managing Unpredictability was another concept contained in the model used in the original study, and was also supported.

**Generation of Subscale Items**

The purpose of this study was to validate items contained in the Hope Maintenance Scale. With the exception of the dimension of Blaming the Victim, the scale items which addressed the dimensions of Hope Maintenance were supported. Another objective of the study was to broaden the scale to include items which transplant recipients expressed as concerns. To fulfill this objective, new items
have been generated from the subcategories of Exceptional Experience, Forced Optimism, Guarded Optimism, Euphoria, and Gratefulness. In addition, items have been developed to address the new category, Normalizing. The original scale items, and items generated from this study are included in Table 3.
Table 3.
DESCRIPTION OF ITEMS FOR HOPE MAINTENANCE SCALE

Dimension: Downward Comparison

Original Items
1. I tell myself that I'm better off than other patients.
2. I convince myself that others have it worse than I do.
3. I remind myself that patients who get complications don't take care of themselves.
4. I tell myself this situation is better than other situations.
5. I remind myself my (partner's) recovery has been smoother than other patients.
6. I convince myself that problems can be prevented by following the diet.

Subcategory: Exceptional Experience
New Items
1. I feel that those who have not lived with a transplant do not understand what I am experiencing.
2. I tell myself I have learned a great deal more than most people who have not lived with a transplant.

Dimension: Optimism

Original Items
1. I don't give up no matter how bad things get.
2. I try not to dwell on complications when they occur.
3. I tell myself the discomfort of procedures is decreased by remaining calm and relaxed.
4. I look at the positive side.

Subcategory: Forced Optimism
New Items
1. I am thankful to be alive, but living with the constant unknowns is difficult.
2. I am hopeful, but when things do not go well, it gets harder to be positive.

Subcategory: Guarded Optimism
New Items
1. I am making the most of my situation.
2. I convince myself that good days outnumber the bad.

Subcategory: Euphoria
New Items
1. I feel that the transplant is the Gift of Life.
2. I have no doubts that life will continue to be wonderful.
<table>
<thead>
<tr>
<th>Subcategory: <strong>Gratefulness</strong></th>
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<tbody>
<tr>
<td><strong>New Items</strong></td>
</tr>
<tr>
<td>1. I feel indebted to the donor of my heart.</td>
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<tr>
<td>2. I have a sense of gratitude that someone was good enough to be a donor.</td>
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<table>
<thead>
<tr>
<th>Dimension: <strong>Belief in a Powerful Other</strong></th>
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<tbody>
<tr>
<td><strong>Original Items</strong></td>
</tr>
<tr>
<td>1. I use my faith to help.</td>
</tr>
<tr>
<td>2. I rely on a higher power to determine how well I do.</td>
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<tr>
<th>Dimension: <strong>Avoiding Painful Material</strong></th>
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<tbody>
<tr>
<td><strong>Original Items</strong></td>
</tr>
<tr>
<td>1. I avoid people who talk negatively about the surgery.</td>
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<tr>
<td>2. I avoid people who are doing poorly following surgery.</td>
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<td>3. I hide my disappointment.</td>
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<td>4. I don't read or listen to medical reports of negative things.</td>
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<tr>
<th>Dimension: <strong>Situation as Temporary</strong></th>
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<tbody>
<tr>
<td><strong>Original Items</strong></td>
</tr>
<tr>
<td>1. I tell myself I will get back to my old way of life.</td>
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<tr>
<td>2. I remind myself life will get better as time passes.</td>
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<tr>
<td>3. I tell myself everything will get better.</td>
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<tr>
<td>4. I think about all the good things that could happen.</td>
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<tr>
<td>5. I set a date when life will be better.</td>
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<tr>
<td>6. I remind myself life will be better in the future.</td>
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<td>7. I remind myself life will get back to normal.</td>
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<tr>
<th>Dimension: <strong>Blaming the Victim</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Original Items</strong></td>
</tr>
<tr>
<td>1. I remind myself this experience will have greater meaning beyond the surgery.</td>
</tr>
<tr>
<td>2. I follow the doctor's orders, so I will do better than patients who disobey.</td>
</tr>
<tr>
<td>3. I assure myself complications can be prevented by not worrying or being anxious.</td>
</tr>
</tbody>
</table>
Table 3. (continued)
DESCRIPTION OF ITEMS FOR HOPE MAINTENANCE SCALE

Dimension: Normalizing

New Items
1. I do not let my life revolve around the transplant.
2. I have become too dependant upon others.
3. I am able to work and this contributes to my quality of life.
4. I live a normal life within limits.

Summary

In summary, five dimensions of the Hope Maintenance Scale were supported as a result of content analysis performed on qualitative data in this study. Blaming the Victim, a sixth dimension of Hope Maintenance, did not emerge as a theme. Four subcategories generated from Fostering Optimism were: Forced Optimism, Guarded Optimism, Euphoria, and Gratefulness. A subcategory of Downward Comparison, Exceptional Experience, was described. An additional category, Normalizing, was developed, and both positive and negative statements which addressed the concept were described. New items were developed to reflect the new categories in order to broaden the domain of the Hope Maintenance Scale.
CHAPTER 5
Discussion, Implications

The results of the content analysis of data from the "Predictors of Quality of Life in Heart Transplantation" study (1988) are examined in the final chapter. Implications for nursing practice and research are discussed. Finally, limitations of the study are presented.

Findings

The purpose of the study was to validate the Hope maintenance Scale, which was developed from data provided by family members of transplant recipients. Content analysis of data collected from 226 recipients was used in this study and revealed hope maintenance strategies that the patients themselves used in adjusting to life with transplanted hearts. By comparing the concerns expressed by the recipients to the scale items generated from concerns of family members, a picture was formed of how transplantation affects patients and partners. Study results validated five dimensions of hope maintenance contained in the scale. The dimensions of Downward Comparison, Fostering Optimism, Belief in a Powerful Other, Avoiding Painful Material or Situations, and View of the Situation as Temporary were supported by the data. The dimension of Blaming the Victim was not a strategy of hope used by recipients.

Several subcategories were also generated from the data. Exceptional experience emerged as a subcategory of
downward comparison. This reflected a perspective of transplantation as an experience unique to recipients. Recipients stated that the transplant experience could not truly be understood by others. Recipients reportedly valued communication with and support of other transplant patients. This was a way to share their unique experience. This sense of cohesiveness may explain the failure of the data to support the dimension of blaming the victim. Recipients reported supporting other transplant patients through the experience rather than holding their behavior to blame for any complications that might occur.

Subcategories of optimism also emerged, which seemed to represent various levels or qualities of optimism. The four subcategories of optimism were: Forced Optimism, Guarded Optimism, Euphoria, and Gratefulness. The subcategory of Forced Optimism parallels the category of forced effort described by Hinds (1984, 1988) in adolescents receiving treatment for cancer. Like the adolescents, heart transplant recipients in this study revealed an effort to take on a more positive view of their situation. The subcategory of Guarded Optimism was also similar to one explored by Hinds (1984, 1988) in adolescents. Personal possibilities was a dimension of hopefulness defined as the extent to which an adolescent believes that a second chance for self may exist. Guarded Optimism reflects these
positive feelings tempered by the realities of difficulties experienced.

The subcategories of Euphoria and Gratefulness were not related to any components of hope documented in the literature. Although transplantation is a chronic process, recipients experience a course of recovery unlike patients with other chronic illnesses. Immediately following transplantation, the recipient has a dramatic improvement in physical and emotional well-being. Subjects who responded with feelings of euphoria or gratefulness may not yet have experienced rejection or other complications. Due to the nature of the surgery, Euphoria and Gratefulness may be components of optimism unique to transplant recipients. Optimism and its four subcategories were used extensively as strategies to maintain hope.

Finally, a new dimension of hope maintenance, Normalizing, was identified from the data. Normalizing allows for maximal integration of the ill patient into the mainstream of society (Holaday, 1984). The patient exerts efforts to overcome societal perspectives and stereotypes of the role of a chronically ill person. By maximizing the patient's abilities, the impact of the illness is minimized. Holaday (1984) proposed that the strategy of normalizing provides a sense of hope for a better future. This hope is maintained by decreasing anxiety with activities such as following the treatment regimen and learning what areas of
the patient's life or functioning are not affected by the illness.

Normalizing strategies were evident in the data in statements that described minimizing difficulties and maximizing the patient's abilities. Recipients stated that they experienced problems similar to those who have not undergone transplantation, and that they simply adjusted their lives to accommodate the problems. Recipients also stated that they resumed old activities or adopted new ones as a way to retain a sense of normalcy.

Threats to normalizing also surfaced in the data as distress due to the inability to work because of physical limitations, refusal of employers to hire recipients, or fear of losing Medicare or other medical insurance. Failure to return to work also resulted in financial instability, which was compounded by the expense of medications. Considering these problems, patients found it difficult to get 'back to normal' and even more difficult to maintain positive expectations for the future. Thus, threats to normalizing are detrimental to hopefulness.

**Implications for Nursing Practice**

Hope is suggested as a positive contributor to quality of life in heart transplant patients. Quality of life is as important to the success of transplant surgery as are survival rates. Nurses have an important role in enhancing the hope of transplant recipients and their families.
Nurses are in an optimal position to offer hope as they care for the patient throughout the transplant process.

Awareness of hope as multidimensional is necessary if nurses are to enhance the level of hope in transplant recipients and their families. Information on the patient's level of hope can be gathered during comprehensive nursing assessment and supplemented with data from continued interactions. The information relative to the patient's use of strategies within each dimension of hope maintenance, should provide insights into how the nurse may facilitate or support the patients' hope. Therefore, nursing interventions are suggested in relation to each of the dimensions of hope maintenance.

The dimension of downward comparison can be utilized by helping the patient to recognize that the present situation is better than situations that could have occurred if alternative decisions had been made. Interventions can also be directed toward building optimism. Assisting the patient with goal-setting is an intervention that nurses can initiate to enhance feelings of optimism. Setting a series of goals which are realistic, manageable, and easily attainable will facilitate feelings of optimism.

The strategy of belief in a powerful other can be supported by the acknowledgement of its importance. An environment should be created in which patients feel comfortable expressing spiritual needs and practices.
Arrangements for pastoral services should be made if requested by the patient or family.

Viewing the situation as temporary is another dimension which can be facilitated by the nurse to bolster hope. The use of imagery may help the patient visualize and plan for a better future. Bringing attention to goals which have been attained and markers of progress that have been made are strategies that may enable the patient to view the situation as temporary. Informing the patient of progress is important, however, the nurse should respect a patient's wish to avoid painful material or situations. This strategy may increase the patient's sense of well-being. Another way to avoid painful situations is to emphasize the patient's involvement in self-care aimed at preventing complications that could occur as a result of non-compliance with treatment regimens.

To foster the patient's sense of normalizing, family members should be included in patient-care, discussions, and decisions. The family is a primary network of support, and attempts to resume family activities should be encouraged. Referral to appropriate state and government agencies that provide financial assistance is another intervention aimed at providing a sense of stability and normalcy to the patient's transplant experience. In addition, encouraging patients to maintain or develop healthy sleeping and diet habits and a regular exercise routine will help them cope
physically and emotionally with the demands of daily living (Gibson, 1988). Finally, the patient's use of normalizing activities may indicate an optimal time for suggestions of hope maintenance strategies. Normalizing could be used as a marker for the initiation of hope building interventions.

Patients who do not exhibit normalizing activities, that is, those who are experiencing threats to normalizing, can also be helped to become more hopeful. Interventions would enhance feelings of optimism, at least to the level of forced optimism. The nurse can suggest participation in a support group. Membership in a support group can enhance awareness of the universality of the experience of living with a transplant. Support groups are also a source of practical information on health maintenance that can facilitate adjustment to the transplant process. Groups which include family members may enhance adaptation to new roles within the family unit, as well. Providing an opportunity for expression of feelings allows restructuring of perceptions to take place and may help patients to perceive their situation in a more positive light (Gibson, 1988).

**Implications for Nursing Research**

The literature review in Chapter 2 emphasized the necessity of hope in coping with chronic illnesses such as cancer, multiple sclerosis, psychiatric disorders, and heart disease. Furthermore, hope has been identified as a
requirement for survival (Nordini, 1952). The concept of hope has been used synonymously with morale, optimism, and faith. However, hope has rarely been operationalized into components or strategies as was done in the primary study, "Predictors of Quality of Life in Heart Transplantation" (Murdaugh & Mishel, 1988).

Content analysis of the data from this study revealed that some strategies were used more frequently than others to maintain hope in the post-transplant period. Several questions for future research have been raised. For example, research to explore the frequency of specific strategies used at other times during the transplant process is indicated. Is there a difference in hope maintenance strategies used by patients awaiting a donor heart? Does time elapsed since transplantation affect the use or success of hope maintenance strategies? Do these strategies differ in patients receiving their second transplant? These questions need to be explored in patients awaiting and receiving different kinds of donor organs, as well. As transplantation becomes more common in various age groups, future research should also examine hope maintenance strategies used by these populations.

Limitations

The limitations of the study stem from the methods employed to collect and analyze the data. Data were collected on the final page of a 15-page booklet which
contained 8 questionnaires. The length of the booklet may have resulted in fatigue, which may have altered the subjects' responses to the open-ended statement. Also, the statement "In the space provided, please tell us anything you think is important about living with a heart transplant that was not covered in the booklet", was worded in a way that directed some respondents to evaluate the comprehensiveness of the questionnaire booklet. In addition, participants who responded to the statement may have been motivated by different levels of hope than subjects who chose not to write a response.

Finally, a limitation inherent in the content analysis methodology is the potential subjectivity of the researcher. Placing data bits into categories according to themes may be altered by misinterpretations or biases. This could be detrimental to the outcome of the study.

Summary

This study has provided information concerning the difficulties experienced by patients and their families following heart transplantation. Psychological adjustment to changes in physical, marital, family, employment, and financial status are necessary if the patient is to maintain optimal quality of life. Hope is a powerful contributor to adjustment and coping in transplantation and other chronic illnesses. Five existing dimensions used to maintain hope following heart transplantation were substantiated in this
study. In addition, a new dimension, normalizing, was generated. Implications for nursing practice and research were addressed, and limitations of the study were discussed.
APPENDIX A

Human Subjects Approval Waiver
TO: Laurie Fasbinder  
409 N. Bull Run  
Tucson, Arizona 85748

FROM: Lee Crosby, D.N.Sc., R.N.

DATE: May 13, 1991

SUBJECT: Human Subject's Approval for Thesis Research

"Validation of an Instrument Measuring Maintenance of Hope in Heart Transplant Patients"

Your research on the above entitled project, requires no further approval for secondary analysis of data as it has received prior approval as an exempt project.

Best wishes with your research.

LC/dbr
Appendix B
Categories With Corresponding Data

DOWNWARD COMPARISON
1006: Living with a heart transplant isn't always smooth sailing; but it's better to be than not to be.
1001: My lifestyle is pretty much back to pre-illness and my recovery has been exceptional.
3012: Within the group I'm the longest surviving transplant...
3019: I strongly feel most would have gave up. But I didn't.
3044: I believe that my involvement in sports (handball in particular) has contributed to my mental and physical well being. I know that I can perform athletically better than most men my age.
3176: I'm extremely thankful but I don't plan to dwell on it like some people do in our group.
3189: I am now the longest survivor in the world and feel I have to do all the interviews to tell people "it works".
3100: As a young person (24 years old), I think the experience of having a heart transplant is significantly different than that of someone who is older and this is often overlooked.
4030: I feel that what I have gone through has made me a better person.
5188: I have heard of transplants who skip or stop taking some of their medicine. I don't understand why they do this.
5157: It improves your appreciation of the hardships endured by people much worse off than you!!!
5041: I am real fortunate that I have not experienced some of the problems that were mentioned in the survey.
5115: I am not like the usual transplant.
7065: My quality of life is not as it was before my sickness but it is a lot better than some of the transplants I have met.

Subcategory: EXCEPTIONAL EXPERIENCE
3072: There is a spirit to life that can't be explained to anyone who has not been sentenced to death and came home free.
3138: I feel that I have learned a great deal more than most people who have not experienced the situation.
3042: Being a transplant- people should have a better understanding of what you go through, and what life is like for you, with your new body - mind - taste - feelings, and etc.
4018: Only we understand really what the experience is like.
You can never know the full extent of it till you have had a transplant, cause no one can tell you or explain what you're going through. Only those of us who have had it know the full meaning.

OPTIMISM

1016: I'm the same person I was only with a better outlook on life!

1001: I am a positive thinker and refuse to accept a short a future.

3146: Second chances don't come very often. Make the most of it.

3173: The best way to get along with a transplant is to keep a positive attitude about everything. I have my good days and bad days as far as physical ability but with a positive attitude thing's go a lot better. I think a positive outlook has a lot to do with a successful transplant.

3012: I'm convinced that 80-90% of survival and as living through an experience such as a transplant or any major illness is having and maintaining a positive attitude about the medical situation and life in general.

3201: I believe that you need a positive attitude no matter what condition you are in...

3036: My post-transplant experience has been extremely positive. I have had no major difficulties since leaving the hospital 1 month after transplant. In general, I feel that I live a normal life.

3068: Love yourself, don't worry - be happy.

3125: Heart transplantation is the ultimate triumph over death. In order to continue that triumph, the patient must concentrate on living.

3098: ...discussing the positive and negatives helps. We do not dwell on the negatives.

3170: Mental attitude is extremely important when trying to get through low times and depressions.

3104: Obviously, the surgery is definitely productive, because it is able to save lives, for without this procedure, we would be dead!

3126: DO NOT GIVE UP!

3183: I feel that I am very upbeat in my attitude and can shrug off almost anything. I have a keen desire to live and I do plan for the future.

3165: Have fun, do everything you want to that you could not do before transplant. Enjoy watching people looking at me doing physical things in awe. Because most people think you should be wheelchair bound. And always keep yourself psyched how great it is just to breathe normally and not have that drowning feeling.
You know, every transplant patient could get a positive outlook and lead a happy, healthy life. We all just need to be shown the way. I would love to show or tell you how I succeeded. It all starts by living for today. Getting the mind on the right track, you'll find that there will be a lot less signs of rejection and medicines will be reduced.

I am still the same person just much healthier. Transplant recipients are not "super people" - we are people who have made a choice - a choice for life.

The greatest thing a patient needs to recover is the confidence we have in ourselves. Without that, we cannot progress in recovery.

When you tell a transplant patient what not to do remind him what he can do.

I must think positive. Do not let things get you down and depress you. Always look for the better side of life.

I think it's important as a heart transplant patient to accept this second chance at life by making the most of each day.

Positive attitude.
Peace of mind.
Having a transplant is wonderful.
Today I feel good and live everyday to it's fullest.
Problems are often (sometimes) a "state of mind" and a positive attitude is helpful.
Life after a heart transplant is what you want to make of it. You must always have a positive attitude towards the whole situation, and you must have a purpose or goal that makes life worth living.
I enjoy life and live it to it's fullest.
Where there is life there is always hope. Don't say can't just say I'll try.
Be positive. Accept what has happened, and proceed on.
This "new" quality of life is much better than was once experienced.
I am able to continue to enjoy "LIFE" and I do.
Don't live like you might die tomorrow, but like you're going to live for a long time.
I feel great and I want to do things.
Rejection is 0 - very good!
As for myself, life has been good.
It's been my experience that as a transplant have successfully survived for a period of years living a quality life...
I apply a lot of credit to my post op success to my attitude. I feel an attitude such as this is as equally important as all the anti-rejection medicine there is.
I did extremely well after my transplant.
I have been very fortunate. I have developed a new look on life. I have a second chance. I look at it as a medical procedure that will work.

Not to permit a guilt complex to effect your positive attitude.

I am able to do almost anything I want to do.

There was not mention of spirit or attitudes of individual heart transplant recipients. And I think they are just about the most important points or access of an individual to successfully overcome a heart transplant.

We are living proof that this surgery is worthwhile.

Heart transplant lets a person get a closer look on life with family, friends, work and all activities. You feel there's so much to do and so little time.

But now I'm healthy.

Short term planning, goals, support, faith, positive attitude.

...you accept your condition and not be so negative about it. I think a more positive approach should be given, and not ones of negativeness.

Always think positive.

I believe "attitude" has been of supreme importance in my immediate post operative recovery and my continued good health. I was and have always been very positive in my thinking and expectancy.

Subcategory: FORCED OPTIMISM

Of course the main thing is I'm alive. However, I am very able to return to work, but no major company as my past employer will take me back, because I cannot be covered by insurance "OF ANY KIND".

I am thankful to be alive, but living with the constant unknown future, complications and medications is hard.

I concentrate on my good days and what I can do but am always fearful when things are not going so well...I am hopeful but when things do not go well, it is very stressful and it gets harder and harder to be positive.

I do not wish to inflict this on my family nor friends. Most of the time life is beautiful and the only time there are mood swings or depression is when there has been some rejection and I have to greatly increase the prednisone and "come down" afterwards.

You are around for a lot of things in the family, graduations, weddings, and births but you don't always feel so great.

Heart transplantation, organ and tissue transplantation in general is a wonderful thing. However, as you can see it
is not without problems. You trade your diseased part for a more usually easier to deal with and treatable disease.

3133:...the day of your transplant possibilities open up and life is within your grasp once again, but on that day you trade one set of problems for a whole new set, and you need as much help handling these as you did the ones before because these are a puzzle to everyone.

3090:Your life may be extended for a while however, based on my experience, the quality of life is poor.

4004:My new heart is doing just great, but all the side effects I'm experiencing from the medications really dims the light of living.

4029:Things have been very good after my transplant except for my hips therefore I can not do a lot of the things I would like to do.

4042:Feeling you always have to "feel fine" when you don't so people won't think you're a complainer.

4012:...I may die at any time. My transplanted heart is not as predictable as a healthy, original organ. But ask me if it was worth it and I don't have to think about the answer.

5063:In the 2 years that I have had my transplant I felt very good but in the past month I have back problems, overweight, fatigue, can't sleep, swelling of ankles.

5263:There is just no way these bills can be paid. I also think there should be some help with the cost of the meds. Other than that it's wonderful to be living a normal healthy life once again.

5135:I have been through a lot of pain and agony but I have no regrets.

5197:There's a lot of complications in having such an operation with all the medication and side effects but can say I am doing well with all of this...

5180:Considering the problems, symptoms, anxiety etc. experienced today, I consider my life to be very worthwhile and fruitful.

5059:It's not a bed of roses, but we are alive.

6030:It seems I have traded one struggle of suffering for another. Thus, I have lived 3 months more than I would have.

7030:Biological survival is important, and for me, it's working well. However, it appears that it will ultimately lead to financial ruin. That's where it becomes difficult to live with a transplant.

8120:...having to deal with medicaid and insurance companies takes any good edge off life and only money could make that better. Still, as I always say, the alternative is even worse.
Right now I'm in much pain from the fractured bones I have. So not as cheerful as I should be.

Subcategory: GUARDED OPTIMISM
Lack of sleep - just so many problems - but I'm a fortunate man and I do enjoy living and look forward to every day.
That he has ups and downs and will never be 100% but will have a full life with proper adjustments.
The "good" days outnumber the "bad" days.
I have learned to live with my complications and discomforts very well, but sometimes they seem to get the best of you. I would never change any part of my life and I would do it all again if it were necessary.
I don't like being dependent on the team and on the medication but I am getting better at accepting it, and accepting myself.
What is important is to recognize that life can be good, maybe not the same as it once was, yet still good.
...I guess I get gritty and hang in there till my ship comes in.
It takes a strong mind to be on this program - you live from day to day no future can you plan - but one loves life he keeps his head up and keeps going. Trying never to give up.
You still have to take chances...I do very well but I have to pace myself.
To know that whatever happens, everything that can be done, has been done!
Everybody is an individual so each recovers to his own level.
I've gotten along so well and had so much support from so many. The invalid fear is still there. I have all the faith in the world but you still wonder if something is going to go wrong...It has been very hard on my family but I always tried to stay on top of everything and never really give up.
My transplant has went very well so far.
I have not had much trouble other than cold or flu for the past 2 years.
It is important to remember that life after a transplant is extremely difficult. I was so sick that I didn't have a choice. But my life will never be the same, my husband and I both believe that we were given a second chance and very lucky to be given one!
Try to live one day at a time and try to make the best of it.
5142: I myself try to get the best out of every day that I can.
5097: Always feel like there is nothing I can't do, maybe not the same way others can, but do it your way.
5042: I would say my plant and my vital organs are holding up very well at this point... If the side effects were relieved, I would enjoy life much better.
5041: I must say that not every day is the greatest, but I have much more good days than bad days and even the poor days are better now than before my transplant.
5115: Rejection is a very good!
6032: I have had no real problems.
6026: I still worry about rejection, but that is a small price to pay for such a wonderful chance at a second life.
6036: I do everything I want but sometimes tire quite excessively.
6004: The heart transplant is good, but the medication causes complications to the mind and body too.
6045: Life can and should be better if you follow the advance given by your doctor...
7041: That life is never normal, but that it is always good. That tomorrow will always be better if you think today was great.
7080: Perhaps there will be dark days in the future but I can safely say to this day after the transplant, life is wonderful.
7086: The side effects of the medications. The burden of loved ones. Don't confuse the above with the joy I have for just being alive today!
8108: I'm happy and hope to contribute to society and my family.

Subcategory: EUPHORIA
1015: Gift of Life, it's beautiful to be able to breath again smell the flowers and trees be able to succeed in life. It's beautiful. No words to describe. I feel very fortunate to be where I am now...
1016: Basically - you really enjoy life - you pay more attention to the world around you and slow your pace down from the rush of things and enjoy living more - everything seems more beautiful and you realize that every minute of every day is worthwhile...
3185: I awake everyday with the joy of knowing I am making the best of each situation whether it be good or bad. I try and challenge myself with each task so that I better myself at everything I do.
3072: You know to live life for what it is everyday with love, zest, freedom!!
I am perfect!

My endurance is excellent. I feel so alive when I finish playing a match of handball, tennis or swimming, hiking, or whatever exercise...and mentally, I'm refreshed. Life is great.

I think that it is a miracle that after 11 years after my transplant, that I'm still alive and living...I just can't believe that it can be done and that it works!!!!!!

The quality of my life has improved beyond my expectations. Sometimes it is hard to believe what has happened to me and how lucky I am to be here.

Was it worth it? Yes! Definitely! Would I do it again? Yes. Did I expect to live this long? Yes, never doubted it.

Attitude! Acceptance! Love! Forgiveness - of self and all others!

I feel real great, everything is going real well...I was having anxiety attacks, but you know what, that's all in the past now. My blood pressure medicine has been cut in half and I feel super.

My doctors are very satisfied with my progress and I could never be happier. Again I live each day as if it was my last day. I'm very happy and positive about life.

To enjoy each day as it comes and not to worry about tomorrow! To take joy and pleasure in those things around me as my children...

None of us is promised tomorrow, but I've had more tomorrows than I would have had without my miracle surgery.

Getting out of bed is special. Every once in a while I pull off the shelf a book that's been waiting a long time, crack it open, and realize: I almost didn't get to read this one.

I think being a transplant is wonderful and every day is exciting and unpredictable.

I enjoy life and live it to it's fullest.

It's great to be alive with a second chance. I enjoy life very much.

I'm glad I'm alive - when my family said "Go for it Dad!" I'm glad I did - it was worth it.

It's great to be alive and feeling good.

The only thing I can say is a person is very lucky and fortunate to have a heart transplant in this modern world of technology and excellent doctors to perform such a serious and miraculous operation.

It's great to go to bed at night, knowing that you will see the sun and flowers the next morning. Things that were taken for granted before the transplant now take on a new meaning. I notice things I never noticed before.
To me, it's great to have a new heart and to have had the experience of it all.

I'm very happy with my new heart, new retired life, and everything in general.

I do anything that I want to do. I hunt and fish - camp, generally enjoy life.

I find living with a heart transplant is a marvelous feeling, since I'm the heart transplant.

Thus far life is great! The hospital staff and transplant team seem to go out of their way to help in any way. My life has taken on a new high just for the privilege of living.

I would say the more important aspect of living as a transplant recipient is fantastic. When your "tank of gas" is almost empty - then it's suddenly filled causes a person to reflect very deeply about life. Having been very near death on numerous occasions, I find "renewed life" very exhilarating...Perhaps you should have asked: Has your life been enhanced? I would say "Ya Damn Tooten!!!!!!"

Subcategory: GRATEFUL OPTIMISM

...just be thankful someone was good enough to be a donor.

I am thankful for my (second shot) at life, and I intend to live it to the fullest.

I feel privileged to have been allowed to receive a transplant and most grateful for the goodness of my donor family and the miracle of modern medicine!

I am very happy and grateful to have been given the opportunity for a transplant.

I stay grateful for my new heart without it I would be dead, my strong desire keeps me going...I'm just thankful there are people who care or it wouldn't have been possible for me to exist.

I am so thankful to be alive and have a chance for more life.

I try to help others who are waiting for new transplants. I also feel gifted to have gotten a heart and try to promote organ donation. This gives me a personal way to thank my donor.

My family and friends have supported me in so many ways. I feel I owe it to them and to myself to do my best to be optimistic and productive for how ever long the Lord allows me to remain on earth.

I should thank God everyday for giving me a new life and I also thank my donor, who ever it was and sometimes
pray for it. Over all I'm most grateful for the second chance.

5083: I thank everyone for the opportunity to be able to live a near normal life. Also all the wonderful doctors, nurses and people associated with the program. I feel privileged to be alive and doing well.

5238: Very grateful of having the heart and being alive.

5151: ...I am happy to be living and thankful to everyone who helped me.

5164: ...it's great to have a second chance thanks to some wonderful parents somewhere down South, a great team of surgeons, and the Lord.

5148: ...one has to be grateful, appreciative and thankful for having received a transplant.

5041: I do work for the Cancer and March of Dimes societies. I also do all the purchasing for my church, Rectory and School, plus I teach computer classes at school. This is my way of showing thanks for my good health.

6026: I will try to do something for society and all the wonderful people that made this possible and got me through the worst of it. I still have difficulty believing I was one of the lucky ones to get a new heart!

7017: I am dealing with this transplant, grateful, thankful, and want to do all I can to use my abilities as a minister of 40 years to help others.

7047: I'm most fortunate to have a new chance at life and I thank everyone.

8007: For the transplant I could not be more satisfied or grateful.

BELIEF IN A POWERFUL OTHER

1015: Mainly to one almighty above - made it possible.

3185: ...with my will and God's blessings, the sky's the limit.

3201: I believe that you need a positive attitude no matter what condition you are in as well as the belief in the Lord...

3147: I found in my situation hope is my best friend along with faith.

3033: The best part for me, was how my faith in God and Jesus Christ was strengthened by all this. I really feel the prayers of other believers all over the US for me (when I was sick) made all the difference. I feel God gave me life back to me. I was an "active" Christian before, but I feel my strength of faith has increased.

3140: My faith in God and praying to Him has carried me through some very difficult times; I have never felt alone.
3133:I am thankful everyday that God has given me that day, but what I would love to ask Him is "WHY? What am I accomplishing? I know I have a purpose to fulfill...I do know God has a plan for me and I'll be here till it's finished...

4040:Living by the book is good.

4008:To retain and count my faith in almighty God - to place my future in his hands to exercise all the will he vests in me!

4048:I prayed a lot and just always thought the Lord would take care of me.

4012:I'm praying more intensely and learning about the spiritual qualities that truly matter - love, joy, patience, peace and compassion.

5255:Have faith in God and don't give up.

5046:I appreciate the fact God perform a miracle and the doctors and nurses perform a miracle with God's help and I am deeply thankful...I should thank God everyday for giving me a new life...

5196:Everyday you wake up from sleep, just say thank you Lord and make the most of it.

5162:But what helps me the most is my faith in Jesus Christ. The doctors do the cutting but He does the healing and I just praise God for the doctors and people involved in the operation but most of all I have to praise Him for my donor.

5174:Have faith and have someone who really cares for you.

5073:...it was the will of God for me to live. He gave me a look at heaven and sent me back and he must have a reason...

5197:...I can also say there is only one thing to do - believe in God and don't worry about tomorrow and live for today.

5164:Church and the bible has taken on a whole new meaning. 5041:...almighty God really stood by me in my time of need.

6030:But I do thank God for each day He gives me also.

6017:For myself the most important thing is a complete faith and trust in God.

7025:I trust my doctors and have faith in my God that I will continue to have a long and productive life.

7080:My trust has been and will be in God, and the doctors as they are given the skill from God to help me enjoy a quality life.

7082:Religious faith in God.

7047:You want to stick with what is real and important - namely your family and God.

7003:I think more emphasis should be placed on your relationship with God where your most help comes from as well as family, friends and people around you. More faith in Him than in your medical team.
My faith in God, and the power of prayer have played a great part in my life before and since my transplant. I'm thankful for my faith in God. This is a great help. I don't know if I'd been able to get this far without it.

AVOIDING PAINFUL MATERIAL OR SITUATIONS
I try very hard to stay away from other transplant patients. Keep out of all stressful conditions. I do not associate with other transplant patients...
I rarely tell anyone I meet that I've had a transplant...
"How do you feel when you meet new people? Do you mention your transplant? Do you hide it?"
Do not dwell on what happened to you.

SITUATION AS TEMPORARY
I know things could be better and that is what I look forward to when I had the transplant.
I have hope that maybe someday things may get a little better.

NORMALIZING
Do not gain weight. Create something physical to do and push yourself to the limit.
Do not treat us like babies. I was sick had an operation and am better.
My priorities as to what is and isn't important in life have changed dramatically.
I lead a very normal life...I rarely think of complications at all. I live for the future, making plans 10 years ahead and thinking about retirement. I work a routine job 48-60 hours a week under stress. I take my medications as a habit and routine, usually without thinking about it a lot. I definitely do not dwell on what has happened.
...transplant patients must be careful not to be too dependent on others for care.
Accept the donor heart as my own and get back to normal life. Don't live with pity and try not to let your family spoil you and make you selfish.
...I seldom think about it and live a normal life within the physical limitations caused by the medications.
I also believe you have to keep active and not sit around feeling sorry for yourself. You know your own potential and limits. Use them to the best of your ability and you will feel better for it.

Twice a day I take a moment to take my drugs, and several times a year I have a biopsy, but these things don't interfere greatly with my everyday activities. I think of myself as a person, rather than a "transplant patient". Being a transplant is only a small part of my life, and although it is an important part, I don't see any reason to make it a major emphasis of my existence.

...one does not always think about their transplant.

In order to continue that triumph, the patient must concentrate on living. To me that means concentration on the animal functions. It means hard physical exercise, active sex, eating well, etc. It also means dedication to the mind (reading, working).

Slow down your pace of living. Stop to smell the flowers. Don't get in a rush.

Patients should be ready to create new rules and expectations for life, not to expect to get back to "normal"...Patients should be cautioned about becoming too psychologically dependent on their doctor.

We need to know how cosmetic surgery could correct the way we look (if we so choose) a year or so after surgery.

I am now aware of what to watch for so I can get help sooner if it starts to happen again.

...we are all subject to be different in most things and should not be expected to live up to a base line of the more successful patients.

Learning to better accept the changes in your body because of the side effects of the meds.

My lifestyle must also include strict attention to health indicators.

Most of the time—I forget about it.

I think it's important to have an interest in everyday things of life and to enjoy doing crafts, exercise etc.

Living with a heart transplant is no different than normal living.

Recognize that a little paranoia is probably normal.

You need something to focus your time and energy on that will be rewarding.

You have to get on with your life and not dwell on the "why me", aspect. Take care as best as you can to prevent complications. Do things in moderation, watch what you do to reduce your chances of infection. Keep in touch with your transplant team. Do what they need you to do so they know how to help should a problem arise. Be truthful.
Don't let the pressures of everyday life, along with your medical problem, and people telling you what they think you should be doing to take care of yourself, get you down.

5197:...don't sit at home and worry about getting sick.
6032:My family has made things as normal as possible...I try to do everything my doctor suggests.
6041:Treat the transplanted heart and the fact you have a transplanted heart as normal. Do not worry about it.
6031:A person with a transplant is no different than anyone else. We love the same or even more deeply than before.
6026:I have to remind myself constantly to warm up my heart before doing anything physical.
6013:...I feel the new heart is mine as if it had never been replaced...It is very important to feel as normal as possible.
6023:Do not pamper or baby the person, let them do for themselves...
7025:I don't look at myself as being handicapped in any way and don't feel sorry for myself at any time.
7023:Problems are not different from those encountered by everyone else. Diet and exercise require some discipline and are important. Avoiding sources of infection (within reason) and taking medications as prescribed are the only differences in lifestyle I can see.
8029:Let them live a normal life. Don't feel sorry for them, they should have it good now.
8108:Getting into the mainstream of life is very important, not being a cardiac cripple.
8082:Treat the transplantee as you would anyone else. I do not feel that I'm abnormal.
8086:...mentally and physically I am basically the same person except for extreme physical activity.

Subcategory:THREATS TO NORMALIZING
1012:The worse things about living with a heart transplant are all the medications I have to take and the constant trips to the hospital for follow-up care and biopsy check-up.
1009:Social Security does not allow me the privilege of working, because of the limited amount of money I can make...This really worries me the most about this medical disability...Now, I have to live like a poor, dumb, un-educated person, just because of my medical problem.
1006:...no one should figure on being able to hold down a steady job. There are too many medical appointments, and too many times of feeling washed out and needing rest. I have a hard time getting any paper work done - I have to get up and move around too much.
The memory machine has gone on strike. Sometimes I sit and drink my coffee in the morning and suddenly I think of my medication and it's 10:30 AM and I can't remember if I took it or not, and I think about last night's dosage.

...became sick all of a sudden and had my transplant 11 days later. This sudden illness and transplant immediately ended my career.

The major thing I don't do that I used to do is play tennis.

The physical changes for women are more dramatic, hair loss, and growth, body changes, premature aging, loss of desire, inability to have children (by doctors orders). It totally changed my hopes and plans for the future. Its been one thing after another with each medication change, always worse so its difficult to pull yourself up time after time.

I do not take drugs and/or medications well. I never even used aspirin prior to my heart problems. All these drugs really have profound effects on me.

I cannot imagine more of a death threat than the advice to "take it easy". This can only lead to malaise...Whenever I think of myself as a transplant patient, invariably I am feeling sorry for myself or making an excuse for something.

It is very difficult to live with the uncertainty of knowing what the results of the next biopsy may mean that you may die.

The worst part, for me, was how I looked.

Disappointment of not returning to work full time, which was promised by transplant team.

I find it very difficult when meeting someone new to explain my shaky hands or my general slowness.

With our conditions being so unpredictable and erratic it is hard to determine when or if a person is able to return to work.

I think the most important thing about living with us is the general ups and downs that we encounter.

I believe that as long as one has to consume this much medicine - it is impossible to function at a rate of living a normal life.

My depressed immune system is why I wear a mask and frighten little kids.

...how discouraging it is for a person with a transplant not to be accepted when returning to work or how hard it is to get a job now that you've had a transplant...

I found it very difficult to face family and people because of my physical appearance. I have become very self conscious and feel the need to explain why I have gained weight or appear puffy.
While insurance covers most there is always unexpected and travel expenses not covered which can cause hypertension and strain. Do not expect things will be normal as before you had your heart problems.

There is always problems cropping up, whether they are big or small.

The adjustment to the drugs was difficult for me and the difference in my weight and difficulty in losing weight.

Due to the high priced bills we can't plan to do anything in advance because of money situations and also if we wanted to plan a vacation in advance we couldn't due to the fact that I don't know how I'm going to feel from day to day.

Being reminded every day of the situation because of the medication regimen from 6AM to 10PM.

Since our lives revolve around our medication and tests other things are put aside that could make our second chance at life more rewarding.

I had not financial stock-pile when I got sick. so trying to live something that resembles a "quality of life" and dealing with "the system" is a constant dilemma.
References


