

UCSF

UC San Francisco Electronic Theses and Dissertations

Title

Family resources and recovery

Permalink

<https://escholarship.org/uc/item/97c2z9qr>

Author

Leavitt, Maribelle Bryde

Publication Date

1988

Peer reviewed|Thesis/dissertation

FAMILY RESOURCES AND RECOVERY

by

MARIBELLE BRYDE LEAVITT

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF NURSING SCIENCE

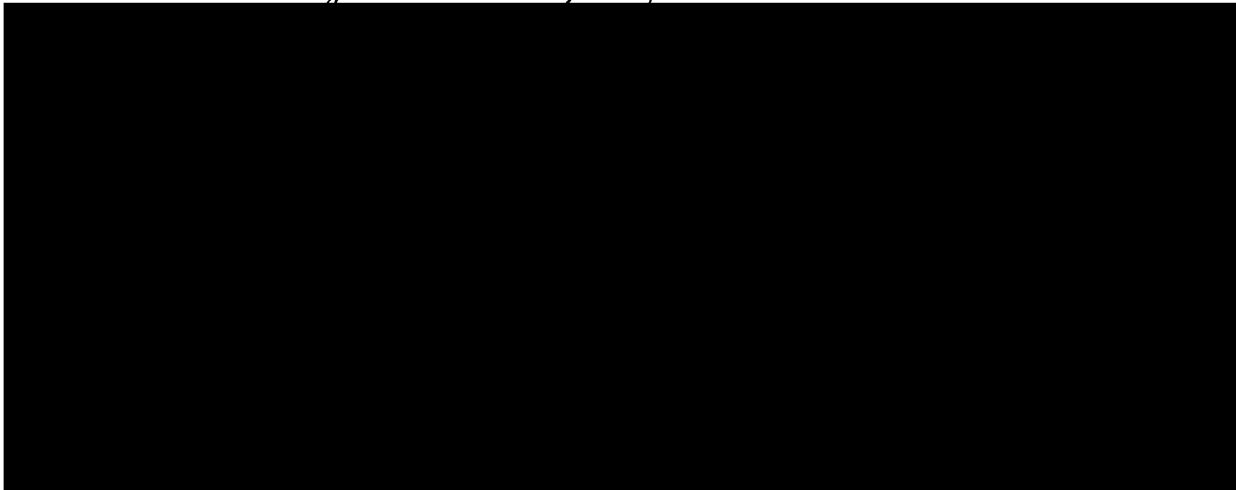
in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco



Date

University Librarian

Degree Conferred: . . . SEP 4 1988

copyright 1988

by

Maribelle Bryde Leavitt

ACKNOWLEDGMENTS

I wish to thank Dr. Joan Ablon and Dr. Leonard Schatzman for their guidance and assistance with the qualitative aspects of this study. Dr. Schatzman's vision and standard of theoretical analysis provided direction toward the possible. At the same time, his understanding and humor supported me through the realities of completing this project. Dr. Ablon's experience, expertise, and understanding provided invaluable perspective and support.

A dissertation is the pulling together of many pieces; a test of the candidate's tenacity and spirit as much as of his or her knowledge or expertise. Dr. Susan Gortner was, from the first, a mainstay intellectually and emotionally. When I became pregnant in the middle of my first year in the program, Susan gave me hope and assurance that this effort could be accomplished and that my children would still have a mother. As I progressed through the program, she guided and gently pushed the process until, piece by piece, the whole was completed. She was meticulous with her attention and direction on this dissertation. Her wisdom is of life as well as letters and she was extraordinarily generous with this wisdom and with herself.

My husband and sons I thank for their love, patience, and understanding. My son, Max, said that he will miss the sound of the printer, signaling the end of my day's work.

Maribelle Leavitt
August 1988

ABSTRACT

FAMILY RESOURCES AND RECOVERY

Maribelle Bryde Leavitt

Twenty-one families were followed from admission of a family member for vascular surgery to three months after discharge. Families were observed and interviewed during the hospitalization, again after returning home, and by telephone. Family instrumentation--the Family APGAR (APGAR), the Family Coping Index (FCOPES), and the Family Inventory of Resources for Management (FIRM)--was combined with grounded theory methodology to study family responses over time and to determine the relevance of the family assessment tools to this clinical population.

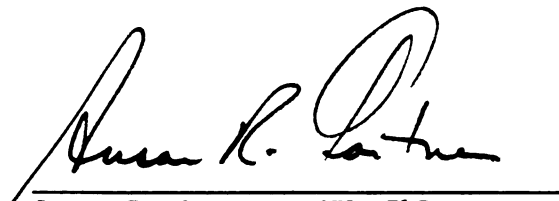
Family integration of the illness and surgery over time, moderated by strategies of containment, emerged as the grounded theory. Containment strategies served to limit the disruption of the crisis of surgery and its associated meanings in the pre-existing family life patterns of functioning. Three phases of the process of integration were identified: accommodation, confrontation, and acknowledgement.

Conclusions of the grounded theory analysis were that containment controlled family disruption but preempted the opportunity for the family to accept and understand peripheral vascular disease or manage its risk factors. A pivotal dimension of containment was the sustained ambiguity of the meaning of the physical symptoms and the purpose of the surgery, which appeared to be poorly understood by the family. The hospital was not a resource for families: families were not mobilized by health care providers for a health care role after discharge.

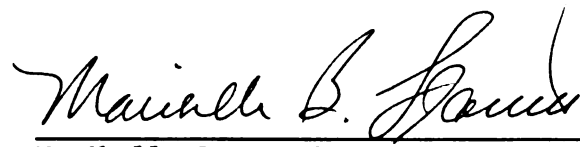
Recovery morbidities were unexpected, poorly understood and more distressing to families than to clinicians. This was particularly so for psychological morbidity (depression, emotional lability and family conflict). Family relationships acted as the primary mediator of information management. Families tended to be isolated in their coping patterns with the exception of the Black American and Hispanic families who drew on extensive social networks for support.

Significant findings of the family measures analyses were compared with the grounded theory analyses. Assessment of families at risk can be made on the basis of low and discrepant family and patient scores on the APGAR. The FCOPEs and the FIRM were less discriminating or valid.

The family measures results corresponded to and corroborated the grounded theory. The theory, in turn provided substantive explanation for the measures' results. The convergent validity of the combined methods supports the utility of this design for family study.



Susan R. Gortner, MN, PhD
Chair



Maribelle B. Leavitt, RN, MS
Candidate

TABLE OF CONTENTS

	<u>Page</u>
CHAPTER ONE: INTRODUCTION	1
Purpose	1
Impetus for the Study of Families and Health Care	1
The Hospital as Therapeutic Access	3
Evaluation of Family Measures	3
Aims of the Study	4
Significance	5
CHAPTER TWO: REVIEW OF THE LITERATURE	6
Peripheral Vascular Disease (P.V.D.)	6
The Scope of the Disease	7
Symptomatology	8
Risk Factors Associated with the Disease	8
Medical and Surgical Management	9
Family Stress and Coping Theory	12
Major Concepts	13
Discussion	15
CHAPTER THREE: METHODOLOGY	26
Design	26
Sampling Plan	27
Recruitment of Subjects	30
Refusals and Problems in Subject Recruitment	33
Human Subjects Procedures	33
Study Settings	34
Instruments	34
Data Collection	36
Procedural Problems in Data Collection	39
Control of Investigator and Other Sources of Bias	40
Data Analysis	42
Study Variables	42
Qualitative Analysis	43
Quantitative Analysis	46
Integrative Analysis	46
Description of the Sample	47
CHAPTER FOUR: THE GROUNDED THEORY ANALYSIS: CONTAINING THE CRISIS: THE FAMILY AND VASCULAR SURGERY	52
The Analysis Trail	53
The Conceptual Framework	55
Integration	55
Containment	57
Family Work	58
The Phases of the Process of Integration	61
Accommodation	62
Confrontation	77
Developing Awareness and Acknowledgement: The Recovery Phase	118

	<u>Page</u>
CHAPTER FIVE: DISCUSSION OF THE GROUNDED THEORY	173
Containment	173
Conditions and Contexts of Containment Strategies	174
The Grounded Theory's Fit with Extant Theory and Research	180
CHAPTER SIX: ANALYSES OF THE FAMILY MEASURES	187
Reliability Analyses of the Family Measures	187
Analyses of Change in Family Measures Scores Over Time	189
Patients' Scores	189
Family Members' Scores	191
Analyses of Difference in Patient and Family Member Scores at Time 1	192
Analyses of Difference in Patient and Family Scores at Time 2	194
CHAPTER SEVEN: ANALYSIS OF COMBINED FINDINGS	201
Results of the Validity Assessment of the Family Instruments	202
The APGAR	202
The FIRM	202
The FCOPEs	203
Validity of the Family Measures in Tapping Family Behavior	206
The FCOPEs	206
The APGAR	207
The FIRM	208
Discussion of the Combined Analyses	209
Contributions of the Family Measures	209
Contributions of the Qualitative Study	210
Contributions of the Combined Analyses	212
CHAPTER EIGHT: SUMMARY, CONCLUSIONS AND IMPLICATIONS FOR PRACTICE AND RESEARCH	214
Summary	214
Accommodation	216
Confrontation	217
Acknowledgement	219
Conclusions of the Grounded Theory	223
Conclusions of the Combined Analyses:	227
The Methodological Study Questions	
The Identification of Families at Risk	227
Value of Proxy Family Measures	229
Implications for Practice	231
Implications for Family Study	235
The Grounded Theory	235
Recommendations for Combined Approaches in Family Nursing Research	237

	<u>Page</u>
BIBLIOGRAPHY	239
APPENDICES	246
Appendix A: Interview Guides for Data Collection	246
Appendix B: Analysis Worksheet Sample	253
Appendix C: Case Histories	255
Appendix D: Recovery Morbidity by Stages	269

LIST OF TABLES

Table 1.	Study Variables and Measures	28
Table 2.	Summary of Socio-Economic Characteristics of the Sample	50
Table 3.	Characteristics of the Study Sample	51
Table 4.	Means, Standard Deviations and Ranges of Family Measure Scores at Two Time Points	188
Table 5.	Coefficient Alphas for Family Measures at Two Time Points	190

LIST OF FIGURES

Figure 1.	Study Design Showing Variables and Observation Points	29
Figure 2.	Containing the Crisis: The Family and Vascular Surgery	56
Figure 3.	Results of the Analyses: FIRM I	197
Figure 4.	Results of the Analyses: FIRM II	198
Figure 5.	Results of the Analyses: FCOPEs: A.S.S.	198
Figure 6.	Results of the Analyses: APGAR	199
Figure 7.	Results of the Analyses: FCOPEs: P.A.	199
Figure 8.	Results of the Analyses: FCOPEs: M.F.	200

CHAPTER ONE

INTRODUCTION

Purpose

This study examined the relationship of family and environmental resources to family's mastery and competency in managing the demands of hospitalization and recovery of a family member undergoing major vascular surgery. The purpose of the study was to extend knowledge of family coping with major surgery and recovery in the context of a chronic, progressive disease, and factors which may contribute to the family's capacity to manage a health care role.

Impetus for the Study of Families and Health Care

A set of conditions has emerged in the present delivery of health care which provides impetus for investigation of the family's experience of major illness and hospitalization and the family's role in illness care and and surgical recovery. Advances in medical treatment have altered substantially the survival trajectory for seriously ill patients (Scott, Goode, & Arlin, 1983). Technological advances in treatment have been accompanied by an increase in serial, episodic hospital admissions, exhaustion of family resources, more specialized care and discrete units of specialists for the patient and the family to deal with (Dracup & Breu, 1978; Ferraro & Longo, 1985; Mailick, 1983; Scott, Goode, & Arlin, 1983). Hospitalizations are shorter and more acute (Oberst & James, 1985), in response to concern for cost containment and as a result of technological advances in care.

As patients are being discharged rapidly after critical hospitalizations, the family of the patient is increasingly asked to take on the burdens of sophisticated physical and psychological appraisal and care of recovering or chronically ill patients and, at the same time, continue to manage the physical, social and psychological needs of the family as a whole. Not all families can manage these demands without cost to either patient or family well being.

In their study of families' adjustment to renal dialysis, Gonzales and Reiss (1981) found that families had considerable difficulty in coping with the demands of serious life threatening chronic illness care while attending to the demands of the rest of family life. One or the other was excluded from the family's attention and resources with the result that either the illness or the family's intactness and functioning deteriorated. In their study, the more competent family seemed to avoid extremes. They were able to use other resources outside the family and altered their patterns of coping to fit the demands of different phases of the illness. Other studies have reported significant psychiatric morbidity and stress syndromes in families coping with severe illness and multiple hospitalizations (Binger, 1969; Kaplan, Smith, Grobstein, & Fischman, 1977; Scott, Goode, & Arlin, 1983). Some families do well, even thrive on these new demands, as these studies have also noted. Factors which influence the family's capacity to manage a care-taking role, and the mechanisms, or processes by which these factors operate need to be systematically assessed, and where necessary, supported by professional efforts.

The Hospital as Therapeutic Access

The event of hospitalization represents a (theoretic) locus of therapeutic access to families coping with serious illness. The hospitalization of a family member may represent an opportunity for the family to strengthen or expand its resources or develop new competencies for a care taking role. It is also possible that the family's experience of hospitalization has no or perhaps a negative influence on its coping capacity. This study sought increased understanding of the contribution of the family's experience of hospitalization to the family's resources for coping with illness and managing recovery.

Evaluation of Family Measures

Standardized measures to assess family problem solving, resources and function exist. It is not known whether these are stable indicators of family constructs or valid under these particular clinical circumstances. Experiences of the patient and family before and during hospitalization, such as illness history, family participation, activity and the nature of their interaction with professional care providers may affect family function. Other factors, such as family role of the patient, length of hospital stay, co-morbidities, family size or ethnicity may also be related to the family's competence in a care taking role.

Both quantitative and qualitative measures were employed in this study to assess the effects of the situational crisis of hospitalization and surgical recovery for major illness on family function and factors in the hospital and recovery situation which may account for these changes.

Aims of the Study

Study aims and questions were:

1. to identify criteria for evaluating family needs for professional support during hospitalization and in preparation for a role as health care resource during recovery,
2. to evaluate methods for assessing family resources and competence for managing the demands of hospitalization and home care.

Answers to the following questions were sought:

1. Can families at increased risk of deteriorated family function or negative physical and psychological recovery outcomes resulting from the crisis of major illness be identified on the basis of standardized measures of family coping and function? (Are family measures valid and stable indicators of these variables?)
2. How do observed family behaviors and interactions in the hospital and recovery situations correspond with standardized measures of their functioning and problem solving?
3. In what ways does the family's hospital experience influence its capacity to manage recovery and home care?

To answer these questions, a multiple case design was employed to examine family experience in hospitals and during convalescence at home through the third month after discharge following major vascular surgery for chronic peripheral vascular disease. A participant observation strategy for the study was used in the hospital, semi-structured interviews and observation for the home visits and semi-structured

interviews for the telephone follow up during convalescence. Additionally, standardized family assessment tools were used to allow triangulation of family appraisal.

Significance

The identification of effective family coping strategies, family function dimensions and environmental supports for families managing the stresses of hospitalization and home care was viewed as a major study outcome. Once identified, these strategies and dimensions might be systematically noted by clinicians in contact with families during the hospitalization of a family member in order to foster them and provide accurate support.

Another, potential contribution is the empirical validation of standardized family function and coping measures through the use of interview and behavioral observation of families during hospitalization and recovery.

CHAPTER TWO

REVIEW OF THE LITERATURE

Peripheral Vascular Disease (P.V.D.)

Peripheral vascular disease (P.V.D.) is commonly used to describe arterial diseases of the extremities but actually refers to a wide range of clinical vascular problems. These include: neurologic dysfunction due to extracranial cerebrovascular disease, abdominal aortic aneurysm, renovascular hypertension, vasculogenic impotence, lower and upper extremity arterial insufficiency and ishenic syndromes, and venous dysfunction of the extremities (Doyle, 1986). The major pathological conditions in the broad category of P.V.D. are arteriosclerosis obliterans, thromboangitis obliterans, Raynaud's disease, venous insufficiency and lymphademoma (Wagner, 1986).

Although rarely a direct cause of death in and of itself, peripheral vascular disease can, however, result in devastating chronic disability and disfigurement (Dolye, 1986, p. 241). Arteriosclerosis obliterans is the leading cause of obstructive arterial disease in persons over thirty years (Doyle, 1984, 1986). This form of arterial disease involves the accumulation of lipids, fibrin, platelets and other cellular debris into and along the lining of the artery which results in intraluminal narrowing and finally, complete occlusion. The evolution of the disease from a simple early lesion to the complex lesion found in adults is insidious, taking several decades to produce clinical symptoms. The mature lesion of atherosclerosis develops toward middle

age, in the third decade of life. At this stage, it is characterized by intimal ulceration, hemorrhage, calcification and/or mural thrombus. Once the patient becomes symptomatic, partial obstruction has occurred and the condition is considered chronic (Wagner, 1986).

Arteriosclerosis is also the major cause of arterial aneurysms, which usually develop in the thinned area of the medial coat of the artery. The dilation of the artery occurs in areas not thickened and hardened by the arteriosclerotic plaque (Rutherford, 1982; Wagner, 1986). There is great variability in the disease process in the severity and the components of the lesions themselves and from individual to individual.

The Scope of the Disease

Precise data about the category of "other arterial diseases" (other than coronary or cerebrovascular) are sparse, but enough is known to demonstrate that these, too pose a major health problem. Figures from 1978 statistics prepared by the National Heart, Lung and Blood Institute (1981) indicate that these diseases cause 55,000 deaths per year, and about one million people are affected. Health expenditures for this group amount to over three billion dollars per year. Prevalence of the "other arteriosclerotic diseases", not in nursing homes under age 65 is 156,000, over age 65, 572,000 and those in nursing homes, 264,400 (Report of the Working Group on Arteriosclerosis of the National Heart, Lung and Blood Institute, 1981). As one of the chronic diseases associated with aging, the problem of peripheral vascular disease will continue as long as life expectancy increases, severely compromising the quality of life (Wagner, 1986).

Symptomatology

Intermittent claudication is the term for the ischemic pain during ambulation. This pain, which results from a decrease in blood flow distal to the obstruction, is usually the presenting symptom. It is described as cramping, aching, burning sensation and is relieved by rest. Early symptomatology progresses to constant pain that is not relieved by resting, coldness, neuropathy with associated parathesias, numbness and deadening. Changes in skin color and eventually, ulceration and gangrene result from the poor circulation.

The symptomatology of aneurysms, another form of peripheral vascular disease, is more sudden and more urgent: abdominal pain, a pulsating mass, pressure on the bowel or other abdominal viscera, decreased peripheral circulation, and shock if rupture occurs. Aneurysms are more usually silent, or found on routine physical examination or arterial studies for other vascular problems. If rupture occurs, the prognosis is doubtful (Wagner, 1986).

Risk Factors Associated with the Disease

Major etiologic risk factors, based on associations uncovered in epidemiologic studies of coronary artery disease include hypertension, cigarette smoking and hypercholesterolemia. Probable, or suspected (non-independent predictors) of the disease are obesity, diabetes mellitus, lack of regular exercise, family history and possibly, psychophysiologic stress (in combination with high fat diets). Men are more susceptible to P.V.D. than women, and the disease becomes more extensive with advancing age (Doyle, 1984).

Control of identifiable risk factors is the mainstay of medical management. The aim of risk factor management is to retard the progression of the disease. Risk factor management often requires significant changes in life style, which are acknowledged to be difficult for the patient and his or her family. Risk factor modification depends upon understanding, willingness and motivation. There is no guarantee of success in the terms of reversibility or cure, but risk management can offer increased lifetime without complications of worsening disease (Doyle, 1984).

Medical and Surgical Management

While the field continues to evolve with the introduction of new graft materials and procedures, such as percutaneous transluminal angioplasty and laser thermal angioplasty, the surgical correction of vascular disease is now common practice and provides a dramatic alternative for patients who once faced certain amputation and permanent disability (McCarthy & Williams, 1985). The patient with ischemic rest pain presents a surgical necessity. Vasodilator drugs have proven to have little benefit in the treatment of peripheral vascular disease. Restoration of arterial blood flow by means of bypass procedures is the most common surgical treatment (Doyle, 1986). Medical management also includes prophylaxis of skin breakdown from infection or trauma.

The literature cites well-established principles for diagnosis and management, success of surgical procedures and progress in limb salvage (Veith, Gupta, et al., 1981; Misretta, Crummy, & Strother, 1981; Bergen, Veith, Bernhard, et al., 1982; Eugene, Goldstone, & Moore, 1976). Little, however has been reported on behavioral and social sequelae of

peripheral vascular disease, its treatment or the patient's and family's role in recovery from surgical intervention and disease management.

Patients with peripheral vascular disease often have complex associated medical problems requiring meticulous management, such as diabetes and coronary artery disease (Hallet, Brewster, & Darling, 1982). The vascular disease leading up to the need for surgery, with its increasing pain and incapacitation, is likely to have become a focus of family attention, concern and accommodation before surgery. If the disease progresses without intervention, ulceration and gangrene may develop and amputation becomes necessary (Dolye, 1986, p. 814).

The medical and surgical management of this chronic disease is palliative, not curative (Doyle, 1984, p. 812.). As one author has stated: "Vascular surgery for arterio-occlusive disease is the surgery of ruins. The surgeon is seldom able to say that he has cured the condition and in the majority of cases, the procedure has been palliative." (Savage, 1983). The progress of the disease, however, can be mitigated by careful medical management and knowledgeable patient and family prophylaxis (Doyle, 1986; Turner, 1986).

Family involvement. The family of the patient with peripheral vascular disease becomes involved with the disease management (to greater or lesser extents) as it assists the patient with surgical recovery, managing life style changes for risk management and helping to monitor the medical problems associated with the disease, such as increased suseptibility to wound infection, poor healing of tissue damage, and signs and symptoms of circulatory compromise. The incorporation and successful management of the psychological impact of serious, chronic illness and its treatment over time becomes also a

family matter (Strauss, 1984). The family, as the matrix of significant relationships and mutual activity surrounding the patient, is a logical focus of preventive, supportive and therapeutic health care efforts, for the patient's health and for the well being of the family as a whole.

In his major overview of the literature relating to the family and health care, Litman (1974) noted that although the contemporary American family is willing to delegate responsibility for the cure and care of a sick member to the hospital, it still retains the traditional function of caring for their sick members who do not need to be hospitalized. While this family care accounts for the major proportion of all illness episodes, how well equipped the family is to provide care remains questionable.

Family coping and long-term illness. Studies of family coping with long term illness and repeated hospitalizations have documented family stress associated with the need to establish and maintain effective relationships with care providers, and continue to maintain a normal life and positive identity, exhaustion of family resources and family conflict (Barbarin & Chesler, 1984; Dracup & Breu, 1978; Kupst et al., 1983; Ferraro & Longo, 1985; Scott, Goode & Arlin, 1983). Gonzales and Reiss's study of family adjustment to renal dialysis found that it was not the illness care itself which overburdened the family; it was the illness management in addition to the regular, developmental demands of family life which was difficult or impossible for families. Most families excluding either the patient's illness or the needs of other family members from the family's attention and consciousness with the result that either the illness or the family's intactness and functioning deteriorated.

Family Stress and Coping Theory

Family stress and coping theory, the Double ABCX model (McCubbin & Patterson, 1982) is a dynamic conceptualization of what families do over time to adapt to crisis by looking at the interaction of the variables, or the basic components of the model. It is an extension and refinement of Hill's (1965) ABCX model of family response to stress. The variables in the original model were A, the stressor event, B, the family's resources, C, the family's definition of the event which interacting together produce a crisis, or severe disruption in the family equilibrium.

The expanded model attempts to account for the family's regenerative power and its relationship to family vulnerability (McCubbin & Patterson, 1982). It recognizes that stresses are not static and frequently are encountered as multiple and complex interrelated demands and needs. Hence, A is now Aa, or the "pile up" of stressful events, changes and stresses associated with the family's efforts to cope with the hardships of the situation. B as Bb includes newly activated resources as well as resources already available to the family. C as Cc includes the family's perception of the total crisis situation, not only the event which precipitated the crisis. X as Xx is now conceptualized as family adaptation, a broader concept used to describe a continuum of outcomes from bon to maladaptation.

Burr (1982) first conceived of "crisis" as a continuous variable, denoting variation in the amount of disruptiveness, incapacitation or disorganization of the family. The crisis, or disruption is one phase in the family's adjustment over time. The family's post crisis,

regenerative power restores equilibrium in the family system. It has been argued that family disruptions may also serve a positive function, stimulating desirable changes in the family's life, as opportunities for growth and family enhancement (Hansen & Johnson, 1979).

Major Concepts

Family adaptation is a descriptive concept for the outcome of family post-crisis adjustment. It is defined as the degree to which the family system alters its internal functions and or external reality to achieve a family system/environment "fit". Adaptation is a reciprocal relationship or process in which family needs are met with environmental resources and environmental demands are met through family resources (McCubbin and Patterson, 1982).

Family resources, which have been considered by researchers in the past decade, include the family members' personal resources, the family system's internal resources, social support and coping. In brief, personal resources include such reserves as economic well being, health and psychological resources (mastery, self esteem, expectation and control, perception) and family system resources, the family's internal function and system characteristics and problem-solving ability. Social support's influence as a mediator of family stress seems to work both by protecting against the effects of stressors and by promoting recovery.

Coping refers to the covert and overt behaviors used by family members to prevent, alleviate or respond to stressful situations. These coping processes include the management of tension, reframing, or reappraising the meaning of problems, and actually modifying the situation itself, taking action. The social meaning also mediates the

severity of stressors' effects by providing explanation and acceptability. Lack of social meaning or highly negative meanings lead to the converse: more negative impact of the stressor/s. Coping strategies themselves can be a source of stress. For example, the need to relieve anxiety and tension may be so great that denial, escape, or loss of emotional control in important negotiations are necessary, and may put the family at a greater disadvantage (McCubbin & Patterson, 1982).

Family stress and coping theory (the Double ABCX Model) is a multivariate and complex set of components which seeks to explain and predict family behavior in response to stress, as well as ways to improve it (McCubbin and Patterson, 1982).

Dimensions of family functioning which appear to discriminate healthier, more effective family systems from less effective have been studied. These may provide a basis for identification of families at increased risk of dysfunction or coping deficit during the crisis of hospitalization and surgical recovery. Family boundary behavior: the family's openness to the environment, their ability to seek information, to actively attempt to cope and master their lives, tolerate conflict and uncertainty, negotiate solutions, to act as a flexible, coordinated team vs relying exclusively on the past for ways to solve problems, resulting in premature problem closure, or authoritarian and rigid, "closed" approach to problems are some of these dimensions (Kantor & Lehr, 1975; Lewis, Beavers, Gossett, & Phillips, 1976; Oliveri & Reiss, 1982; Pratt, 1976).

Whether or how these dimensions or family dispositions are subject to change, or are predictive of family behavior under the circumstances

of this study is uncharted. Effective vs ineffective coping must be assessed on the basis of the fit of the family's strategies with a complex field of forces, and the family's own collective consciousness (Thorne, 1983).

Discussion

The role of the hospital. Research based on the Double ABCX framework must account for many concurrent processes. Latitude for discovery of new processes in conjunction with appraisal of known factors may offer a way to confirm parts of the model while exploring new dimensions or refining ones already delineated. For example, a particular interest is the observation of the family's coping patterns and internal family system resources in interaction with the hospital environment: how the situation (rules, care routines, physical environment, events and interactions with care providers) affect family adaptation.

The potential for family growth and change as well as deterioration in the adaptation to crisis is perhaps the most exciting and intriguing aspect of the model, particularly for the study of contributions of the hospital experience on family adaptation. Does the crisis of hospital treatment of a family member bring forth new or different problem solving capacities, or change in the family's function?

The hospital can be a source of relief and comfort in the form of care, hope for cure and recovery or improvement of disease or disability. But it is also a source of great distress. Stresses associated with the hospital environment for patients are many and have been studied, along with preexisting correlates of these stresses (Volicer, 1975, 1977, 1978).

Hospitalization for serious illness can precipitate a crisis even within the most highly organized family structures. Illness disrupts family roles and forces families to change and reorganize in order to successfully regain their equilibrium (Daley, 1984). Studies have documented higher stress levels in the spouses of patients than the patients themselves, whose stress levels were well above the normal population (Gilliss, 1983; Oberst & James, 1985; Silva, 1979). The high spousal stress levels are often associated with exhaustion and the need to maintain a cheerful demeanor with the patient and with the hospital staff (Oberst & James, 1985), as well as the uncertainty and distress of the patient's condition and care.

Needs for information, hope and a caring attitude were ranked highest across studies of professionally constructed family needs statements during hospitalization (Daley, 1984; Mathis, 1984; Molter, 1979; Norris & Grove, 1986). Other studies have indicated a divergence in family vs. professional assessment of family needs and a more complex, "normalized" construction, or definition of serious illness and treatment by the family (Anderson, 1981; Norris & Grove, 1986; Robinson & Thorne, 1983; Thorne, 1985).

Families do not perceive a staff role in regard to their needs (Hampe, 1978; Molter, 1979). Families' anxieties are tightly bound to the realistic threats of the patient's care in the hospital, and needs for their own personal (physical or emotional) comfort are not perceived as important (Hampe, 1978; Lust, 1984; Stillwell, 1984). Family needs for care are unmet (Hampe, 1978; Leavitt, 1975). However, the total family effort to focus and "be there" for the patient in the hospital, in spite of hardship and family sacrifice, is a source of family self-

esteem and mastery, in spite of the costs of personal and family disruption and sacrifice, at least initially (Barbarin & Chesler, 1984; Gonzales & Reiss, 1981).

The definition of the situation. The family's definition of its situation seems to be key to understanding its responses to illness (Knafl, 1985; Schwenk & Hughes, 1983). The family's definition has both stable and reactive features. These need to be examined separately and together. More stable features are the clarity of community/social norms for family behavior under this particular stress and the individual family's norms' fit with these (McCubbin, 1979). Reactive features include constructed meanings and interpretations of lived experience.

Striking discrepancies between the family's observed struggles and deterioration under the pressure of chronic illness and its scores on family symptom and family function instruments were noted by Gonzales and Reiss (1981). The family's need for normalcy and self esteem, as well as its definition of coping well as it deals with serious, life threatening illness noted by Barbarin and Chesler (1984) may account in part for this discrepancy, or positive bias on the family measures. (In Barbarin & Chesler's work, the families' definition of coping well was to be able to continue to function, rather than freedom from distress.) Families' construction of serious illness was more "normal" than professionally derived constructs and dependent on the family's values and need to preserve self esteem in studies by Anderson (1981), Robinson and Thorne (1983) and Thorne (1985). Families may discount the current situation in their self reports and assessments, taking a broad view of their history and functioning in their responses. Gonzales and Reiss

(1981) suggest that the family's reorganization around the illness, either to the exclusion (sacrifice) of the illness or the ongoing, developmental needs of the rest of the family dictates their responses to the study scales. If the illness has been excluded by the family, they do not include it in their self assessments. If the family has organized around the illness, they were unwilling to report distress (or perhaps did not experience distress) in their newly acquired care taking role. The patients scores in both cases, however, were in negative contrast to the family's.

Research approaches. Advantages of combining qualitative approaches, such as validity checks and latitude for subjects to address issues and problems from their own perspectives and according to their own priorities, with quantitative measures for family study have been noted in family studies (Kupst, Tylke, Thomas, Mudd, Richardson, & Schulman, 1982; Oberst & James, 1985). The meaning and construction of lived experience as reality and the processes of change are most directly accessed by naturalistic observation and interview. Standardized instruments provide efficient access to data but are often proxy measures of experiential variables, and thus are subject to biases of social desirability and family dynamics. The power of convergent validity of naturalistic study with objective measures, when it occurs, however, is unequalled. The absence of convergent validity provides an opportunity for further analysis and insight into methodologic yields in family study (Haynes & Chavez, 1983).

Distortion and bias of reactive features and effects of members' disclosures during interviews, or on self reports must also be considered in the analysis of the content of family study. Data

gathered from the family as a whole, or from a couple together tends to be more positive (Haynes & Chavez, 1983). Individual data about the family may be different from data gathered from the family as a whole, and are not necessarily representative of the family as a whole (Fisher, 1982).

Trajectory data. Longitudinal studies (Dhooper, 1983; Gortner, et al, in press; Kupst et al, 1982; Oberst & James, 1985) of families coping with illness or recovery from heart attack, cancer surgery and heart surgery have overlapping findings about the family recovery trajectory, although methods differed. During hospitalization, families are anxious and dedicated to the patient's care, in spite of life disruption. They are also symptomatic, with sleeplessness, headache, loss of appetite, lack of concentration. The leveling off of the initial disruption and stress after the first few weeks after discharge, the substitution of different stressors, such as the patient's narcissism, the spouse's reactive illness, the "let down" after the rapid discharge, and the unexpected difficulties of physical recovery at home are other common findings.

Spouses continue to have a higher incidence of emotional problems after discharge (Oberst & James, 1985; Dhooper, 1983). Depression takes the place of anxiety, and anger over the patient's egocentricity is replaced by guilt. Distresses after discharge were largely unexpected by both patient and spouse (Oberst & James, 1985; Gilliss, 1983).

These trajectory data also demonstrate some of the difficulties of measuring possible effects of hospitalization on the family's function and coping. When a whole new set of stressors presents itself, will family measures reflect the effects of these more than any effect of

hospitalization on family coping? Families may have learned specific coping skills and strategies or developed new explanations and philosophical insights about the illness in the hospital which could "carry over" into the recovery period. They may also feel "cast off" by the hospital at discharge, bewildered and overwhelmed by care demands and unexpected stresses of recovery, or a combination of the two in a wide range of possible variations. The study of family resources and possible contributions of the hospitalization experience to the family's capacity to manage a critical health care role must be able to "sift through" information derived from different data gathering methods to validly describe and account for changes (or lack of change) in the family's resources.

Summary and study objectives. In summary, studies reviewed here support the need for qualitative study of the experience of families in the hospital for major surgery. It is hoped that the combination of the qualitative appraisal with quantitative standardized assessment may reveal the extent to which the family's predispositions and functioning guide its coping patterns and experiences during hospitalization and recovery, and/or how the lived experience of the crisis of hospitalization and recovery might affect these predispositions.

Family stress and coping theory, the Double ABCX model, provides a comprehensive blueprint and explanation of the processes of family adaptation to the crisis of major hospitalization of a family member and the transition to home care. The framework's acknowledgement of the family's potential for growth or deterioration in the adaptation to crisis is central to the aims of this study of the contributions of hospitalization to the family's adaptation.

Objectives of this study were derived from extant literature on family coping and family measurement and assessment. These are:

1. to observe for change over time in family function and coping resources with the family's experience of hospitalization as the major intervening variable,
2. to empirically validate three standardized measures of family coping and family function by observing for correspondence between these and actual family behavior and adaptation in hospital and in recovery,
3. to describe the contribution of other factors to variation in families' management and experience of hospitalization and post hospital care, such as families' interactions with care givers in the hospital setting, the physical and psychological recovery of the patient, families' participation in care and associations of family demographic data with patterns of interaction and family participation, and
4. to examine the variation in families' experience and management in the hospital in relation to families' post hospital mastery, morale, functioning and resources.

Working hypotheses. Competing, "working" hypotheses regarding the relationships of study variables are suggested by the literature and the current state of knowledge and inquiry of family adaptation to illness and guide this inquiry. These are two:

1. Standardized measures of family resources, problem solving and function will remain stable over time and act as valid indicators and predictors of family adaptation and outcome,

2. Situational variables, such as family patterns of participation in care, experience with care and the care environment, the physical status and recovery of the patient, the presence or absence of other, concurrent family crises or demographic variables, will contribute to variation over time in families' management and adaptation to hospitalization and recovery.

Definition of terms.

1. Stress. Psychological stress is a relationship between the person or family and the environment that is appraised by the person or the family as taxing or exceeding resources and endangering well-being (Lazarus & Folkman, 1984, p. 21); a demand-capability imbalance (McCubbin et al., 1982).
2. Emotional distress. This is an indicator of stress (unpleasant feelings of distress of which people are aware) (Pearlin and Schooler, 1978).
3. Mastery. Mastery is defined as a psychological resource and an outcome of the coping process; the expectation of being able to cope combined with the actual experience of coping well in the anticipated situation (Pearlin and Schooler, 1978); equated with confidence (Lazarus & Folkman, 1984, p. 66); and competence (Moos & Schaefer, 1984, p. 10). Mastery is also defined as " the extent to which one regards one's life chances as being under one's own control" (Pearlin & Schooler, 1978) includes fate control, flexibility and managerial abilities (McCubbin, Nevin, Cauble, Larson, Comeau, & Patterson, 1982). Finding an acceptable balance between

accepting help and taking an active and responsible part in controlling the direction and activities of ones life preserves a satisfactory self-image and maintains a sense of competence and mastery (Moos & Schaefer, 1984, p. 11). Mastery contributes to morale.

4. Morale. Morale is an outcome and process indicator of coping efficacy and adaptation, how people feel about themselves and their conditions of life. It is related to avowed happiness, satisfaction, and subjective well being. Affect, or morale in a specific encounter is very much in the foreground and shifts as the encounter with stress unfolds (Lazarus and Folkman, 1984).
5. Adaptation. This is defined as a continuum of outcomes that reflect family efforts to achieve a balance in functioning at the member-to-family and family-to-community levels. Adaptation ranges from positive bonadaptation to negative maladaptation (McCubbin et al, 1982).
6. Coping. Coping encompasses behavioral responses of family members and the collective family unit to prevent, alleviate or respond to stressful situations, manage the hardships of the situation, resolve the intra-family conflicts and tensions as well as acquire and develop social, psychological and material resources needed to facilitate family adaptation (McCubbin, Cauble, & Patterson, 1982). Coping strategies will refer to those specific approaches, plans and behaviors the family utilizes in the hospital situation.

7. Resources. Family resources include the family member's personal resources, the family system's internal resources, social support and coping. Personal resources include such reserves as economic well being, health and psychological resources of mastery, self esteem, control perception. Family system resources include the family's internal function and system characteristics and problem solving ability. Social support mediates family stress by protecting against the effects of stressors and by promoting recovery through psychological and material means (McCubbin, Cauble, & Patterson, 1982).

How families cope is another dimension of family resources. Coping processes include the management of tension, reframing or reappraising the meaning of problems and action to modify the situation. Social meaning of the family's situation is also a resource, mediating the severity of stressors' effects by providing explanation and acceptability and even a guide for coping behavior.

8. Experience. Experience is a concept in this study that is preferred to the more discrete and limited ones such as perception. Experience refers to the family's perception, sensation, emotional and cognitive responses, and interpretation of environmental and internal stimuli. Experience as a study construct accounts for the constructed and dynamic, constantly evolving nature of reality for families as they progress through the hospitalization, homecoming and recovery of their relatives. The family's

experience is a product of its sense of vulnerability and mastery, its successes and failures, its strategic decisions and its philosophy. The family's experience must be assessed in the family's own words, from its view. Observation of experience must be validated with the one who is being observed, i.e., "what was that like for you? " Kestenbaum (1982) maintains that subjective experience is fundamentally important not simply because it is a subjective accounting of a pre-existing objective reality, but because lived experience is reality.

CHAPTER THREE

METHODOLOGY

Design

A twenty subject sample, correlational longitudinal design was combined with an aggregated, single case design to study family coping patterns from hospital admission to three months after discharge. The methodologic capacity of single case research for detail and intensity make it ideally suited to the investigation of multivariate phenomena, such as family data represent. A serial run or accumulation of cases over a specified period of time can build generalizability when a systematic, replicable approach is maintained (Kazdin, 1982, Rabin, 1981). The serial single case design allowed the investigator to complete analysis of the within family data as each case is completed. Group analysis of the between family data was undertaken after the sample was complete.

The grounded theory research approach, utilized in the qualitative aspect of the study is conceptually parallel to this design. Generating theory and doing research are two parts of the same process in the grounded theory approach (Glaser, 1987). The constant and continuous data analysis yields theoretical constructs which guide further data collection and analysis, toward the emerging core construct, or theory. Generalizability and reliability are derived from constant, comparative analysis and theoretical sampling (Strauss, 1986, p. 16). These dimensions, and the requirement of close, "dense" examination of data

are compatible with the aggregated single case design. The study design and variables are presented in Table 1 and Figure 1.

Sampling Plan

A representative sample of patients hospitalized for major vascular surgery for peripheral vascular disease was sought together with adult family members (18 years or older) of these patients who were most actively involved with their care. Surgical intervention for peripheral vascular disease provided a situation that was suited to the study of family resources for managing a stressful hospitalization and surgical recovery in the context of a chronic progressive illness. The surgical procedures sampled included aorto-femoral bypass grafting, aortic, iliac and femoral endarterectomy, abdominal aortic aneurysm repair, renal artery reconstruction and femoral popliteal bypass grafting. Patients with serious perioperative or operative complications were excluded from the study. An age range of forty five to sixty five for the patients was considered to comprise a sample group that was roughly comparable in terms of family developmental stage and representative of the population.

For the purposes of this study, a family was defined as the patient's significant, close, social network, with whom he or she resided with prior to the surgery and/or with whom he or she will be residing after discharge. The "discharge" family, where the patient goes for recovery care, was the primary criterion of selection. Bloch (1983) defined the family for "clinical occasions" as the "ad hoc" family, those persons immediately involved with the problem, who are

Table 1

Study Variables and Measures

STUDY VARIABLES AND MEASURES: * THE FAMILY IN THE HOSPITAL: RESOURCES, TRANSACTIONS WITH THE HOSPITAL ENVIRONMENT AND RECOVERY	
<u>PHASE 1 (ADMISSION)</u> Family function (APGAR) Family problem solving attitudes and resources (F-COPES) Family internal re- sources for management (FIRM I, II) Family's view of resources (INTERVIEW) Expectations, appraisal of current situation Events leading to hospitalization (INTERVIEW) Family function Family interaction with caregivers (OBSERVATION)	<u>PHASE 2 (HOSPITALIZATION)</u> FAMILY FUNCTION IN RESPONSE TO: (Interview and Observation) <ul style="list-style-type: none"> • Events • Institutional structures • Ongoing demands of family life (Pile Up) (Interview and Observation) Family Interactions with Care Providers Family Participation in Care
<u>PHASE 3 (HOME CARE)</u> Family function (APGAR) Family problem solving attitudes and resources (F-COPES) Family internal re- sources for management (FIRM I, II) Family's view or resources (INTERVIEW) Appraisal of current situation Effects of hospitalization/ experience on family coping Morale (INTERVIEW/ OBSERVATION) Family function (OBSERVATION/ INTERVIEW)	

**STUDY DESIGN SHOWING VARIABLES AND OBSERVATION POINTS:
THE FAMILY IN THE HOSPITAL:
RESOURCES, TRANSACTIONS WITH THE HOSPITAL
ENVIRONMENT AND RECOVERY**

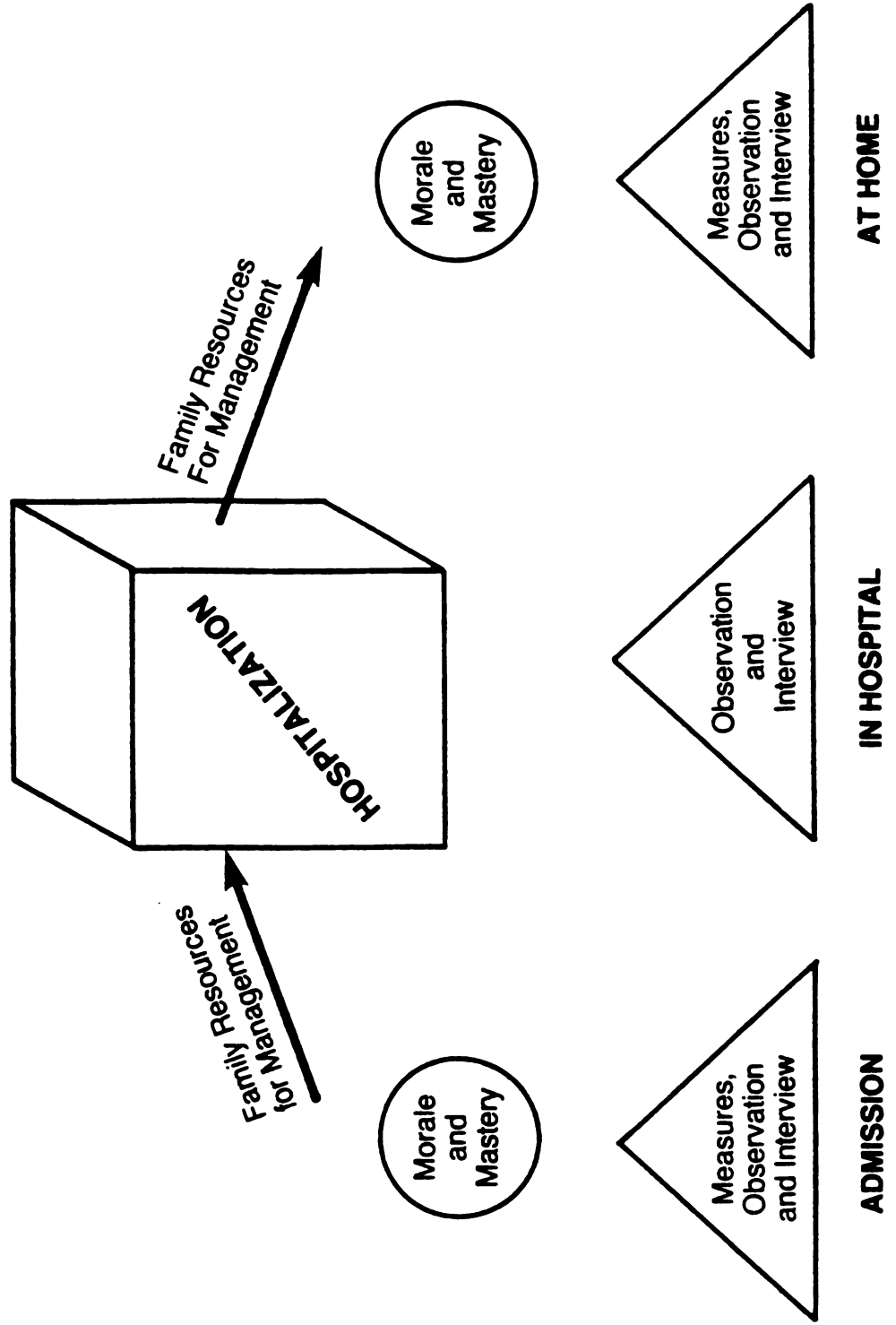


Figure 1. Study design showing variables and observation points.

assembled to assist with its solution. This "ad hoc," clinical family describes well this study's selection criteria. Family size was not a determining factor in sample selection, but only the most directly involved and active members were to be included in the study.

The sample size of twenty families was required for between family (group) statistical analyses of study variables in addition to the detailed qualitative study and analysis of within family change and adaptation over time. A subsample of at least five ethnically similar families was desired to observe for systematic differences in families' experiences by culture.

Recruitment of Subjects

Initial contact for gaining access to the study population was made with the clinical nurse specialist and administrative nurses of the vascular surgery unit in a major medical center. Original estimates were that the sample of twenty families of patients undergoing aorto femoral bypass grafting could be recruited from this setting in four to five months.

Contact was made with the four attending surgeons of this care unit to obtain access to patients for study recruitment. At the request of the department secretary, letters with the study protocol and abstract were sent to each. Initially, one surgeon of the four agreed to allow access to patients on the basis of the letter; subsequently, after telephone and personal follow up to the initial letter, two more surgeons agreed to research access to their patients.

Six weeks passed at the initial study site without the admission of any patients meeting the study criteria. Research entree to a second

site, a major, urban hospital, was initiated. This hospital's three attending vascular surgeons were contacted to obtain approval and access to patients for study recruitment. All consented and directed the investigator to their secretaries for their operative schedules for access to appropriate cases.

Because of the (unusual) shortage of patients meeting study criteria at the time of the study's instigation, it was also decided that it would be appropriate to widen the study criteria to include other major vascular procedures (femoral popliteal bypass grafting, abdominal aortic aneurism repair and renal artery reconstruction). Age was also increased to include patients up to 75-years who had no other major medical problems.

The first subject was recruited from the second site on May 11, 1987, six weeks after the study began. That subject was followed by the second on the next day, the third on May 27 and the fourth on June 20 (also at the second site). The fifth subject was recruited from the first site, on June 18, the sixth patient from the second site on the same day and the next nine from the first site over the following seven months, for a total of 15 patients and 15 family members.

A total of six patients along with their involved family care partners were recruited from a third site, a community hospital in another nearby city. Recruitment from this site began September 1, 1987. Once again, access to patients was gained by first obtaining approval from the hospital's research and human subjects committees and then by contacting the attending vascular surgeons. Three surgeons from one cardiovascular group practice were contacted and all agreed to study access to their patients.

All sites were canvassed for potential subjects by the following methods:

1. Calling the vascular surgery department secretary to check the operative schedules for the participating surgeons.
2. Calling the hospital care units to double check the schedules for admissions and "add-ons".
3. Calling the surgeons private offices and checking with their secretaries.
4. Personal contact was made with all of the surgeon's secretaries, and the investigator's card was taped to their desks.

Once notified of a potential subject's scheduled admission, the subject was "tracked" by calling the hospital admission's office for information. When the patient was "in house", the investigator went to the care unit, read the chart for study criteria, and made personal contact with the patient to recruit them for the study.

A similar procedure for subject recruitment was used at the third site; however, the office operative schedule was unreliable. Patients were often admitted directly from the diagnostic laboratory or were not scheduled with the office. A master's degree prepared and research experienced nurse on the cardiology service staff was hired to recruit subjects and collect data during hospitalization. In four of the six families recruited from the third site, the patients and families were recruited after surgery during the perioperative period due to the irregularity of the admission sequence and procedures.

Refusals and Problems in Subject Recruitment

In all, five patients and families (20% of those approached) refused to participate in the study; three from site 2, one each from site 1 and 3. Two subjects (10%) dropped out of the study during the perioperative period; both were from site 2.

Reasons given for refusal to participate included: the wish for privacy, a "bad" experience with another research project, a wife in psychiatric treatment, "not interested" and interference with AA program participation. Those not continuing stated: "don't like your questionnaires", "not interested in continuing", "cardiac complications after surgery" and "too nervous now". The actual number of appropriate cases admitted during the early period of subject recruitment was far below estimates, and required the addition of sites, as well as widening the study criteria to include more procedures, as was noted.

Human Subjects Procedures

The study protocol was approved by the Research and Human Subjects Committees of all three study sites. Family members were oriented to and prepared for the process and experience of being observed. Appointments for observation and interviews were arranged with the family's and the patient's participation and consent, and in coordination with care routines so that these would not be disrupted. Subjects were informed that the study data were aggregated around the study questions, and that families would be referred to by subject codes for data analysis. The investigator explained the purpose and effort involved in responding to the family measures and was available to answer questions or concerns which might arise in relation to the measures or any other part of the study.

Study Settings

The study settings included the three hospital environments for vascular surgery care, i.e., the intensive care, step down and regular care units, the patient's room, the family waiting room and other incidental areas of these three major, urban hospitals. Interview and observation of families also took place in the families' homes after discharge and by telephone.

Instruments

The Family Coping Index (McCubbin, Larsen & Olson, 1981) is a thirty item questionnaire developed to identify effective problem solving and behavioral strategies used by families in response to problems or difficulties. It taps the family's internal (individual to family system) and external (family to social environment) interaction, on the hypothesis that families operating with coping behaviors on both levels of interaction will adapt more successfully to stressful situations. The FCOPE operationalizes the coping dimension of the Double ABCX Model of family stress and coping, integrating the pile-up, family resources and meaning/perception factors. Five subscales refer to the two different coping dimensions; acquiring social support, reframing, seeking spiritual support and passive appraisal, rated on a five point Likert scale. Reliability coefficients (Cronbach's Alpha) have been determined for all the subscales, and range from 0.64 to 0.84, with the higher ones in the external family coping subscales. The Cronbach's alpha for all scales together is 0.86 (McCubbin & Olson, 1985).

The Family APGAR (Smilkstein, 1978) is a five item questionnaire designed to assess the family's satisfaction with aspects of family life and function. Components of family function measured by the instrument include: adaptation: how resources are shared or assistance given; partnership: how decisions are shared, or mutuality in family communication and problem solving; growth: how nurturing is shared, or the freedom to change; affection: how emotional experiences are shared, or intimacy; and resolve: the time commitment of family members to one another. It is a short instrument, allowing a range of five possible responses (0 to 4) in Likert scale format for each of the five items. Scores range from 0 to 20, corresponding to no to high satisfaction with family function. Validity was established by correlations with other measures of family function (APGAR/Pless-Satterwhite $r=0.80$, APGAR/therapist estimates $r=0.64$ and tests on clinical and normal populations, which established its power to differentiate between the two. Reliability was established on 486 college students, yielding a Cronbach's alpha of 0.80 (Smilkstein, Ashworth & Montano, 1982).

The Family Inventory of Resources for Management (FIRM) (McCubbin, Comeau & Hoskins, 1981) assessed the study constructs of mastery and internal family strength. The first of two subscales of the FIRM (McCubbin, Comeau & Hoskins, 1981) measures family esteem and communication, including items which reflect respect, shared feelings, mutual assistance, optimism, problem solving ability, encouragement of autonomy. The second subscale includes items that reflect resources in the dimensions of the family's sense of mastery, family mutuality (togetherness, cooperation emotional support), and physical and emotional health. Together they comprise a thirty one item self report

questionnaire. These subscales assess family function and morale, as well as competence and physical and emotional health. Validity for the FIRM has been established by significant, positive correlations with other family assessment instruments. Subscales I and II correlated positively and significantly with (differentiating) high and low conflict families coping with chronic illness (McCubbin & Patterson, 1982). The FIRM has internal reliability of .85. These instruments served as baseline and comparison (dependent variable construct) measures.

Data Collection

Field observation, interview and sample survey with standardized measures were used to collect data during the patient's hospital stay from admission to discharge and during recovery at 72 hours, ten days and one month and three months after discharge.

Data gathered at the time of admission included family demographic descriptors: family size, age patient and relevant family members, family role of the patient, ethnicity, education and socioeconomic levels and family perception of resources. Descriptive data regarding illness development, level of knowledge, events leading to hospitalization, and effects on family life were also gathered at this time and current coping and interaction patterns and concerns were noted. Patients and family members were asked to complete the first round of family function (APGAR and FIRM) and coping (FCOPES) measures at this time. About half of the subjects completed the questionnaires at the time of admission. The others did so during the perioperative period.

Field observations, including interviews, were conducted periodically during the hospitalization, with an emphasis on observing "transitional blocks" in the family's experience, such as the day of surgery, the intensive care period, the early and late phases of hospitalization on the general care unit, and the day of discharge. These periods of transition represented points of (theoretically) heightened vigilance and coping demands, due to the need to accommodate to a new situation. Transitional points along a continuum of the experience of hospitalization for the family also represented an opportunity to assess care givers' contributions to the family's adaptation, such as assistance with anticipation of and preparation for a new and potentially distressing experience.

Interview and observation during these points or phases focused around study questions. Families were asked to chronologically review events and transactions, with an emphasis on the identification of family concerns, the family's approaches to dealing with these and the identification of environmental resources. Open ended, rather than structured interviews were used to encourage the family to explore their experiences and concerns according to their own priorities.

Sampling transition periods also provided a relatively comparable sampling of situations, events and conditions. Efforts were also made to sample these situations at similar times of day and for the same length of time. Observational periods had to be arranged with the family and coordinated with other care routines, and exact matching of observation times was not always possible (some families did not come to the hospital on the day of surgery, some patients were discharged precipitously, etc.).

Post hospital adjustment was sampled 72 hours after discharge by telephone, after the first two weeks at home by home visit, at one month and at three months after discharge by telephone. Further, post hospital adjustment was assessed on the basis of the family's functioning, competence in problem solving, their mastery and morale and their self assessment of their general situation. The family's view of the hospitalization as resource for recovery was ascertained. The progress and demands of the patient's physical recovery were noted and used for comparison and data analysis. Interview guides for data collection for hospital visits and recovery monitoring were developed and used (see Appendix A).

Measures of family functioning (the Family APGAR) problem solving attitudes (the FCOPES) and internal resources for management (the FIRM I & II) were readministered in the recovery period (after ten days) to compare with the admission (baseline) measures.

Fisher (1982, 1985) has noted that a vast majority of family research is conceptualized in transactional (reflective of transactional unification into a whole that is different from the sum of its parts) terms but assessed in relational terms (two or more family members' reports or scores "related", or combined and contrasted in some way to indicate a characteristic of the unit, by the investigator). Only data from naturalistic observation can reflect truly transactional level assessment. Relational data are qualitatively different. They are "constructed" family data. Both kinds of family data were collected in this study.

Family members were interviewed separately and together in naturally occurring groups (the "ad hoc" family). Data from individual interviews were later compared with the yield from group interviews.

Procedural Problems in Data Collection

Procedural problems in data collection were anticipated as a result of the complexity of tracking potential subjects from multiple sources, i.e., physician's offices and hospital units, and determining whether surgical/medical complications might make the family's experience untypical. Scheduling times for interviews and field observations, family fatigue, technical problems on the hospital units, such as unanticipated changes in care routines, were also thought to be potential problems in recruitment. Actually, very few cases were missed in the tracking.

Families at times may have experienced the study as a burden; however, they did not directly indicate this fact to the investigator. The family's behavior was one clue to fatigue; a concerted effort was made to schedule calls or meetings at convenient times.

Maintaining an effective balance between the need to establish and maintain positive rapport with the families and patients and continue to gather data was a constant challenge in the study. Methodological notes kept by the researcher note fear of being intrusive, questioning the frequency or timing of calls or hospital visits. A particular concern were instances in which the researcher was advised of events or information by staff that families did not mention. Another was managing the neutrality of the researcher role in the clinical context. At several points, the researcher provided needed information or advice

when it was necessary, i.e., to see the doctor for a draining incision or to make a referral for psychiatric consultation for a patient who was clinically depressed and ruminating about the hallucinatory episode she had had in the hospital. Intervention, advice, answers were given only after subjects had been asked for their approach: "If I were not here, what would you do?"

Control of Investigator and Other Sources of Bias

The potential bias from effects of observer's presence on family interaction and modes of interacting with the hospital environment was acknowledged, as was the potential "prompting" and organizing effect of interviews or assessments on the family's awareness and behavior. It was expected that the families would accommodate to the presence of a stranger after an initial period of adjustment as other naturalistic studies have shown (Hansen, 1983, Kantor and Lehr, 1975), and their enduring patterns of interaction would be valid indicators of the study variables. The family's behavior toward the investigator was considered to be a datum of interest in itself, since it theoretically serves as an example of the family's general system response to outsiders.

The investigator maintained a neutral but friendly and concerned relationship with the family. The investigator did not participate in care giving activities; but the family was informed that in the case of a clinical emergency, the investigator would assist in obtaining appropriate help.

The investigator's clinical orientation and knowledge of family dynamics, family pathology and health was also considered to be a source of observer bias. Regular consultation with research advisers who are

not clinicians was undertaken to neutrally approach the data collection and its appraisal and interpretation. The presentation of data in its raw form as well as in categories and the investigator's analytic decision trail for the qualitative data also provided evidence for the investigator's logic and conclusions (Sandelowski, 1986).

The use of multiple methods allowed the assessment of correspondence or discrepancy between observed family behavior and (potentially) idealized self reports. The investigator remained blind to the instruments' results while gathering and coding of the qualitative data.

A possible testing effect was acknowledged due to the relatively narrow (20 day) interval between the first and second administration of the family function measures. The ten day to two week post discharge point for data collection (home visit) was chosen because it corresponded to Oberst and James (1985) observation that their subjects seemed to change after an initial time period of ten days to begin to attend to new concerns and frustrations in their spousal relationship and in their own lives. These new concerns were less directly related to the physical recovery, which for most families in their study, was well under way. A testing effect was considered to be mitigated by the fact that the families would be, by ten days to two weeks after discharge, in a completely different phase of illness management: at home and having to manage care routines on their own. The hospitalization experience would nevertheless be fresh in the families' memory. Families were instructed to answer questionnaires with primary consideration for their present, rather than their ideal or past situations.

Data Analysis

Study Variables

Analyses of study variables examined family coping and resource measures' correspondence with observations of family behavior and interview data during hospitalization and recovery with particular attention to the possible contributions of hospitalization (the families' transactions with the care environment) to family resources and management during recovery. Observations of family behavior, interactions with care givers and experiences in the care environment were analyzed in conjunction with family coping and resource measures to account for change over time.

Variables examined included:

1. family function, problem solving, internal and external resources in response to the demands of hospitalization and recovery as measured by FCOPEs, APGAR, FIRM, interview and observations of family behavior in the situation.
2. family mastery and morale in the hospital and after discharge as measured by FIRM subscales I and II, interview and observation.
3. family size, composition, ethnicity, economic and education level, age and sex in relation to family adaptation and recovery outcomes.
4. patterns of family participation in hospital and post hospital adaptation as measured by interview and observation of family behavior.

Qualitative Analysis

The qualitative data were analyzed by two approaches: grounded theory, and a survey analysis of the field data based on study questions and other descriptive data of study variables such as the type, frequency and duration of physical symptomatology during recovery, family behavior (tasks, roles in relation to surgical recovery and disease management over time).

Grounded theory is the "systematic generating of theory from the data" (Glaser, 1972, p. 2) "without any particular commitment to specific kinds of data, lines of research or theoretical interests." The theory emerges from the data, and is not selected or classified according to pre-existing categories or classifications (Glaser, 1978). The research is guided by the emerging theory. Study questions are utilized as sensitizing foci for data collection and analysis. Latitude for discovery of new dimensions of family coping can increase the complexity and explanatory power of extant frameworks, such as the Double ABCX model of family stress and coping, when there is there is conceptual fit.

The grounded theory approach to data analysis (Glaser, 1978) was utilized to allow for discovery of processes and the development of explanatory schemes of family behavior in the situation of this study' circumstances without prior committment to theories of family interaction and coping. Indeed, emerging theory; the ongoing, rather than "final" conceptualization of the data, typical of grounded theory, generated concepts questions which were not preconceived, and which surprised the investigator. These questions could then be pursued as data collection continued. For example, the concept of Emotional

Distancing, which became the building block for the core concept of Containment, emerged about half way thorough the study. It was possible, not only to "go back into the data", but also to gather new data about this phenomenon as observation and interview continued.

The analytic process in grounded theory consists first of open coding, or "running the data open", "fracturing the data into analytic pieces which can then be raised to a conceptual level" (Glaser, 1978, p. 56). Theoretical memos are written about the codes and categories, in order to force the analyst to think and "transcend" the empirical data, to ask questions and to guide further analysis. Open coding is painstaking and slow, and should proceed "line by line", or word by word, so that conceptual density is achieved. (Glaser, 1978, pp. 52-60, Strauss, 1987, pp. 59-64. Codes are provisional at first, and the data are re-examined as conceptualization proceeds. "In vivo" codes, coined by the subjects, emerge from the study and provide a powerful and sensitive organization of the data. Eventually, core categories and their dimensions, (conditions, interactions, strategies and consequences) are selectively coded and an integrated, grounded theoretical construction of the data emerges. Reliability and validity are established by the "audit trail" of the researcher's logic and construction of the theory from the empirical data, which are laid out in the writing of the report. A core variable's (or variable construct) validation is through its "saturation" in theoretically constant comparative samples (Glaser & Strauss, 1967).

Reliability and validity assessments in qualitative work are decisions made by the investigator, through replication of the researcher's observations and confirmation by different manifestations,

(variation and contrast cases) of the same construct (Glaser & Strauss, 1967).

The coding of qualitative data proceeded continuously throughout the study. Field notes were coded conceptually, observing for patterns, sequences and clusters of variables. Provisional codes were established. These were re-worked and reordered as data collection and analysis proceeded. The coding paradigm (Strauss, 1987, p. 27) was used to dimensionalize the codes and categories into conditions, sequences, interactions, strategies and consequences. Coding eventually centered around the researcher's selection of a core category: "a pattern of behavior which is relevant and problematic for those involved, toward a theoretical construction. The actual coding and theoretical progression will be described in Chapters Four and Five. The qualitative data will be presented in their unreduced state, to provide illustration and examples of the codes and categories.

Discrepancies in families' interpretation of their situation and in professional assessment of the same situation were important data for this study, and were noted and analyzed. Originally, it was planned that families who were comprised primarily of one involved person, such as spouse, would be treated as a separate comparison subgroup to the larger involved family group in the data analysis. One of the discoveries as the data were analyzed was that one family member emerged as the primary care partner. Subgroupings for analysis, therefore, were according to family role of the patient vis a vis the care partner: spouse, or "other", which included sibling, parent or child.

There were no non-traditional (legal or consanguine) family member care partners in the study. One family of two male friends who had lived

together for 20 years was recruited for the study, but dropped out during the perioperative period. Two separate cohorts for analysis by age, a younger (45-64) and an older (65-72) were to be established for data analysis because it was felt that these constituted different developmental family groups by activity, vigor and family relationships. This did not prove to be the case.

Quantitative Analysis

The family measures were scored and analyzed for change from admission to two weeks after discharge and for difference between patient and family scores at the two time points. Four planned comparisons (matched pair t-tests) were used to analyze the family measures for difference across time and for patient or family role by subscales I and II for the FIRM, all five subscales of the FCOPES and by individual items for the APGAR.

Other variables such as sex, age, and family role were analyzed in conjunction with the family measures. Socio-economic status, risk factors, surgical procedure, and length of hospital stay were analyzed in conjunction with the family measures, but were not entered into statistical analysis due to the small sample size (in order to preserve statistical power).

Integrative Analysis

Integrative analysis of combined data took place after the independent analyses of the qualitative and quantitative data. Comparisons of family measures and qualitative data were made conceptually, by survey of the field notes and the family measures'

scores and on a group (mean) and individual case by case basis. Analysis worksheets were constructed for the integrative analysis and are displayed in Appendix B.

The contribution of difference as well as correspondence in patients' and family members' perception, experience and self reports are valuable data for professional evaluation of family level care needs (Ball, McHenry & Price-Bonham, 1983; Fisher, 1982, 1985; Leavitt, 1982). The case by case analysis examined discrepancy between family member and patient at each measurement time point against the observational data in order to determine if scores were valid indicators of family function and stable across time.

Conceptual integrative analysis searched for logical patterns of relationships and meanings between study variables measured by qualitative and quantitative methods. Theoretical constructs generated by grounded theory were analyzed for fit with the extant major theoretical model of family stress and coping, the Double ABCX Model, operationalized in the family measures.

Description of the Sample

The sample consisted of 21 patients and their family care partners, 42 subjects in total. The mean age of the patients was 58.8 years. The age range was 45 to 72, and the modal age was 59 years. There were 4 patients aged 45 to 50, 3 aged 51 to 58, 7 aged 59 to 65 and 6 aged 65 to 72. There were 10 male and 11 female patients.

The family roles of the care partners were 14 spouses, 4 children, 2 siblings and 1 parent. The sex of the family care partners was 9 males, 12 females.

The surgical procedures sampled were nine aortofemoral bypass grafts, four aortic aneurysm repairs, three femoral popliteal bypass grafts, three femoral or aortic or renal artery reconstruction and one aorto-iliac, one femoral artery endarterectomies.

The mean length of hospital stay was 9.95 days, the range was 5 to 19 days. Patients with pre-existing or associated coronary artery disease totaled seven. Of these, four had undergone coronary bypass grafting prior to this hospitalization. Postoperative complications of this sample included five patients with atrial fibrillation and five with post operative hallucinatory episodes of varying severity.

The patient's occupations included five housewives, five retired, two bus drivers, two accountants, and one each salesman, land developer beautician, insurance adjuster, financial planner, lumber worker and hotel maid. The care partners' occupations included seven housewives, two retired, two real estate agents, and one each bank teller, investment banker, auto repair shop owner, janitor, accountant, attorney, liquor store owner, guard, psychiatric technician and engineer. Care partners who were employed or worked outside the home totalled eleven (half the family member sample).

Seventeen of the 21 patients returned to their own homes after discharge. The other four returned to: a hotel near the hospital, a mobile home brought to the vicinity of the hospital, a sister's home and a son's home. There were nine patients who resided more than fifty miles from the hospital. Only one patient returned to her home alone. Her daughter and granddaughter took turns sleeping at her apartment for the first two weeks after discharge, however.

Patients and families were recruited from three sites, all major urban hospitals. Nine from site 1, five from site 2 and seven from site 3. In the majority of the subject pairs, (patients or care partners) 13 completed high school or had some additional education after high school, such as secretarial certificates. Four in the subject pairs held college degrees, although none were higher than baccalaureate degrees. Four had less than high school education.

There were 12 subject pair (families) with "white collar" occupations (clerical, business managers, engineers, accountants) and 9 representing the "blue collar" occupations (laborers, drivers, beautician). Retired subjects were clarified by their former occupations. Income levels were: three families with annual incomes in excess of \$100,000, eight with incomes of \$40,000 to \$75,000, six with \$10,000 to \$25,000, and four with less than \$10,000.

A three factor index was constructed from family income, education and occupation, and used to rate the subject families from one (the lowest in the sample) to four (the highest). The factors were averaged, but the level one group happened to represent the families with less than high school education, incomes below \$10,000 and blue collar occupations. Two families were level one, six level two, nine level three and four level four. A summary of socio-economic characteristics of the sample are displayed in Table 2. A summary of sample characteristics are displayed in Table 3.

Table 2

Summary of Socio-Economic Characteristics of the Sample

(number of families)

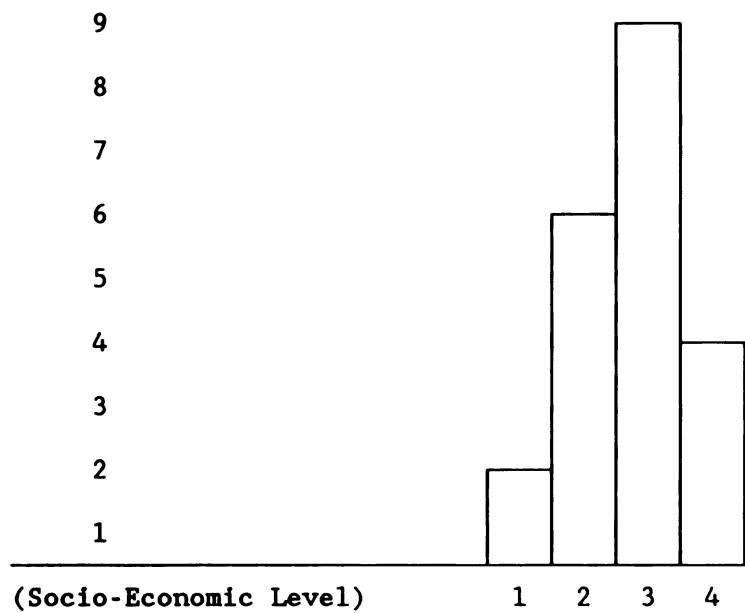


Table 3

Characteristics of the Study Sample

SAMPLE DESCRIPTION

N = 21 Patients
 N = 21 Family Members/Primary Care Taker

Age of patient: \bar{x} = 58 r = 45-72

Sex of patient: M = 10 F = 11

Family Role of Primary Care Taker
 Spouse = 14
 Child = 4
 Sibling = 2
 Parent = 1

Surgical Procedures:
 Aorto-Femoral Bypass Graft = 9
 Femoral-Popliteal Bypass Graft = 3
 Abdominal Aortic Aneurism Repair = 4
 Aortic/Iliac/Femoral Endarterectomy = 2
 Femoral/Aortic/Renal Artery Reconstruction = 3

Length of Stay
 \bar{x} = 9.95 Days
 r = 19 Days

Patients with Coronary Disease = 7
 Status post Coronary Artery Bypass Graft = 4
 Patients with episodes of Post Operative Atrial Fibrillation = 5
 Patients with Post Operative Halluncinatory episodes = 5
 Patients Rehospitalized During Recovery = 5

Families residing out of city from hospital = 9
 Home care domicile first ten days after discharge:
 own home 17
 mobile home }
 hotel }
 sister's home 1
 son's home }

CHAPTER FOUR

THE GROUNDED THEORY ANALYSIS

CONTAINING THE CRISIS: THE FAMILY AND VASCULAR SURGERY

A family lives with peripheral vascular disease over time. At first, the signals or symptoms of this developing disease are not obtrusive. They occur intermittently and infrequently. They are also ambiguous. The feet are not always cold; the cramping is infrequent. As the disease progresses, the leg cramping worsens, the feet cannot seem to ever get warm and the subsequent discomfort and disability become quite severe and obtrusive in the family's life. For the patient, walking, even from the couch to the kitchen, becomes a chore to be avoided.

How does this developing disease affect a family's life? How does the family respond, and what kinds of conditions seem to make a difference in the way the family responds or adapts? At what point is treatment sought? What is then the family's role?

For the patients in this study, the treatment was surgical: revascularization of the affected limb by bypass graft or endarterectomy. How does the family manage the hospitalization for this major surgery? What are the family's conceptualizations or interpretations of surgery and hospitalization, and how are these constructed? What accounts for differences in the way the family approaches and deals with the hospitalization? What do they learn from their experiences in the hospital?

During recovery, what problems do families encounter and how are these problems defined and managed? What definition of recovery do families construct, and how does this construction affect their adjustment to the patient and his disease over time? What factors account for differences in family outcomes from this major health event in the family's life?

The grounded theory is presented in terms of the conceptualization of the process of the family's adjustment and responses over time as it emerged from the data.

The Analysis Trail

As the first patients and families were followed through hospitalization and early recovery at home, it was noticed that they did not address the issue of underlying disease. Reference to the need for the surgery was made in terms that bounded and particularized the problem: "a blockage", "problem with the blood flow", "need to bypass the blockage", "open the blood flow", "repair the bulge", "relieve the pain", "be able to walk again, get around." This apparent absence of concern about their disease may have been a reflection of the context or circumstances: a surgical definition of the problem as the patient and family approached and dealt with the surgery itself. Or it may have been a lack of understanding. The surgery addresses the blockage or the aneurysm, and not the disease, with a bypass graft, a repair, an endarterectomy to improve the flow of blood.

The absence of reference to their actual diagnosis: peripheral vascular disease, and prognosis in terms of a chronic and progressive

disease was in remarkable contrast to the clinical realities of their situation, however, and persisted in concert with a number of mediating factors throughout the recovery course.

Surgical intervention for nontraumatic peripheral disease is essentially palliative. As one surgeon stated in surgical rounds attended by the researcher: "As the time interval in studies increases, patency rates for grafts are no longer valid since the surgery treats the symptoms and not the underlying disease and its inexorable advance." (Ehrenfeld, 1988.) Did the patients and families know this eventuality?

Further investigation of this question revealed that, in most cases, there was some knowledge, some awareness of a disease process, and even some concern. Knowledge was fragmented and pieced together, however, and sometimes accurate, sometimes not. Questions about the illness or its future implications were raised with the investigator in research interviews that sought data about their understanding of the problem creating the need for the surgery. The striking observation was that neither the patient nor the family care partner pursued these questions although they were encouraged to bring up and explore these important concerns with their physicians or other professionals involved in their care.

After brief forays to try to understand and comprehend, they seemed to retreat. There seemed to be a "stopping off" of their concerns and questioning, an opening and then a closing off, a tentative exploration, and then a turning away. Asked why they had not explored their concerns with their physicians, there were a variety of responses, leading in turn to different hunches and more exploration.

This early finding informed the data collection and analysis. Other manifestations of the behavioral pattern of turning away, retreating from direct confrontation with their illness under different circumstances emerged and were added to the analysis, until the central, core categories of containment and integration emerged and provided conceptual explanation for the data. Comparative analysis of different conditions, or variables in the families' trajectories was used to refine the emerging theory and to explain the differences in the process for families.

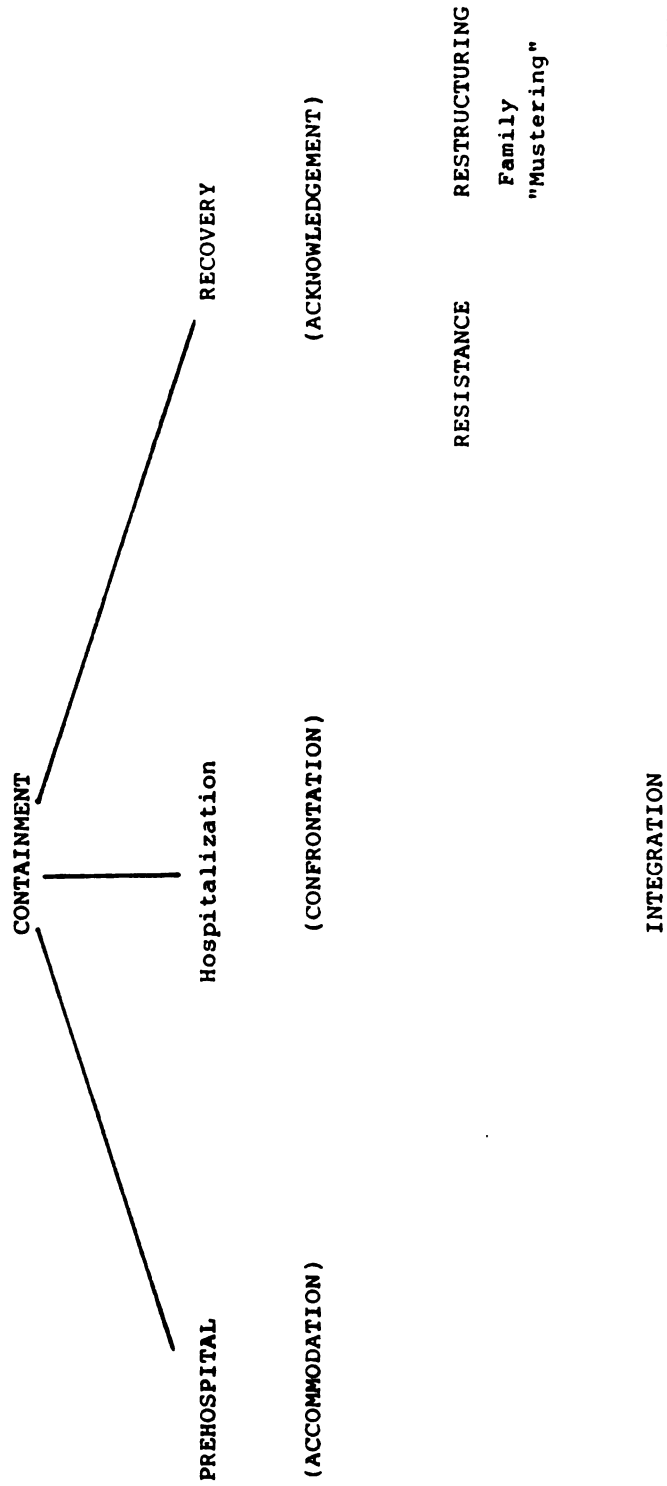
The Conceptual Framework

The central organizing scheme emerging from the data which explained the family's management of the events of vascular surgery and recovery was identified as the process of integration. Integration was moderated by strategies of containment put into motion by various conditions over time. Two case histories of two different family situations over the study trajectory are included in Appendix C. These may serve the reader as holistic views of the analytically separate parts of the theory as it is presented here. The conceptual framework is illustrated in Figure 2.

Integration

Integration was operationally defined as the ongoing process of interpreting and responding to the events of the illness and surgery in such a manner as to maintain the integrity of the family relationships

Containing the Crisis: The Family and Vascular Surgery



Maribelle Leavitt R.N.D.C.NSc.
 Department of Family Health Care Nursing
 University of California,
 San Francisco

Figure 2. Containing the crisis: The family and vascular surgery.

and the normal flow of the collective activities of the family's life. Integration included the family's developing realization or acknowledgement of the surgery as palliative intervention for a chronic, progressive disease and work toward an accommodative construction of this reality for the family's life and function, as well as the health of the patient.

Inherent in the construction were the notions of family agency, or capability and influence, learning about and undertaking the work of stemming the progression of the disease (risk factor management). Integration was both a process and an outcome in this explanatory scheme.

The entire process was conceptualized in terms of its trajectory over time from the first awareness of symptoms, the family's accommodation to the patient's increasing disability and symptomatology, the search for treatment, the surgery and hospitalization, and the early and later recovery after discharge.

Containment

Containment was the major category for strategies by which families regulated the impact of the events of vascular surgery and dealt with the ambiguity and distress of their changing situation. Intrinsic to the concept of containment was the notion of the limitation of harm or impairment, a kind of damage control. Damage was conceptualized as the spread of the consequences of the problem to the rest of life in terms of negative identity change and family disruption. Psychologically, containment strategies served to control the escalation of distress.

Containment was selected as a core conceptual category because of its conceptual fit with the patterns of family responses and behaviors observed throughout the crisis of surgery and recovery. It encompassed the notions of control and regulation, but went beyond these to consider the family's need to preserve stability and continuity, to maintain the familiar structures of family life in the face of the threat of chronic illness to family life.

Containment was observed in the families' interactions among themselves and with others, including professional care providers. It was evident in the families' nonconfrontational, unassertive, controlled, passive/opportunistic behaviors and in their "next event" rather than future-oriented approaches to situations and problems associated with the illness, treatment, and recovery. Containment was also observed in the family's limited, or bounded, interpretations of the surgery and its implications for their lives and the health of the patient. The family's efforts to contain the crisis in the service of family stability, however, often cost the family the opportunity to "muster" themselves for the work of containment in a more constructive sense: the "damage control" of the advance of the illness.

Family Work

The family's adjustment and responses were conceptualized as kinds of work: knowledge work, relational work, psychological/identity work, health, and home work. These five kinds of interrelated work were seen as taking place over time and under different conditions with

consequences for the family's life and function and the patients health by three months after discharge.

Knowledge work was operationally defined as the family's activity of gathering information (learning) about the nature of the illness requiring surgery, its treatment, and implications for present and future family activity, tasks and functions for health maintenance. Included is the family's construction of the meaning of new information and its assimilation, or fit, with existing knowledge. Over time, it was seen as developing realization, regulated by strategies of containment and conditions present in the changing situation families encountered. Knowledge work also referred to the family's work to anticipate health related events and changes, to orient themselves to new environments and changing roles and responsibilities (i.e., jurisdictional changes from home to hospital and home again) and to coordinate these with the ongoing activities and demands of family life (family maintenance).

Health work was defined as recognizing and interpreting signs and symptoms of the illness and the surgical recovery and making decisions to act on these assessments. Health work included the determination of what is a clinically dangerous or hazardous situation and calling for help. The discrimination of recovery versus illness/disease-related symptomatology is part of health work. (Recovery symptoms, such as fatigue or pain are expected and natural; bleeding and infection are not. Some symptoms are "in between", like depression, and are managed with more difficulty.) Health work was also direct, clinical activity: changing dressings; sterile saline soaks; and monitoring rest periods, activity, and health risk behavior, such as smoking, diet and exercise.

Health work depended largely, although not completely, on knowledge work.

Relational work was defined as the work of social negotiation and the management of interpersonal relationships, both new and existing under changing circumstances and conditions. Relational work referred to managing relationships within the family and the family's relations with those outside the family, including authoritative care providers. Included was the family's division of labor, assignment (and reassignment) of roles and tasks over time. Recognizing and meeting ongoing emotional and developmental needs of all family members as well as the patient, balancing and juggling, were all a part of relational work. The interpretation of the rules of the situation was also relational work to maintain smooth interfaces, reduce uncertainty and conflict (avoid confrontation) in encounters with care providers, in the hospital setting, and with one another.

Psychological work was conceptualized as the work of identity management and performance control. Included was managing distress, or becoming emotionally overwhelmed and handling oneself in such a way as to preserve a positive self-identity (to be a good patient, spouse, competent caretaker). Psychological work encompassed work to construct the definition of these roles and to maintain positive identities in changing circumstances. Comfort work, i.e., role taking and providing emotional support, combined psychological work and relational work in the service of identity management and performance control.

Home work referred to the routine physical maintenance tasks of family life: earning work, paying the bills, cleaning, cooking,

shopping, transportation, preparing the home for the needs of a recovering patient, safety and security.

All these kinds of work were performed in the contexts of the others, all of which, coordinated, yielded a form of integration of the physical, emotional and social structures of family life, e.g., routines, interests, order and illness. The work functioned strategically to contain the crisis, or disturbance, so as to ensure the integration of the family life and order.

Ultimately, there is some transformation in the structure and integration of family life as a result of their accumulated experiences. Most families in the study, however, did not achieve a family level acknowledgement of the realistic implications of the need for surgery in the progression of the disease or a "mustering", or pulling together for the work of risk factor, or disease management over the time frame of this study. A few families had more positive outcomes in the sense of disease acknowledgement and management and provide contrast cases for the analysis of the data. What factors accounted for this variation?

The Phases of the Process of Integration

Three overlapping but analytically separate phases of the process of family integration over the illness trajectory from events leading to hospitalization to three months after discharge were constructed from the data. The three phases were defined by conceptualizations of the major task or family activity at that time. These three phases were: accommodation, which corresponded to the first illness development phase up to the time of admission to the hospital; confrontation, which

corresponded to the period of hospitalization; and developing awareness/acknowledgement, which referred to the recovery period after discharge.

Accommodation

Accommodation conceptualized the family's management of the developing illness, the search for treatment and events leading to hospitalization for surgery. Accommodation is defined here as fitting or adapting to the illness. The families adjusted, or accommodated to the patient's increasing disability by modifying their function to fit or compensate for the patient's increasing disability.

Although no patients presented at admission with ulceration or gangrene, action to modify or correct the pain and disability for the most part was delayed until these symptoms had reached severe proportions and until the patient's and the family's life had changed significantly to accommodate the illness's advance. As one family described, "Used to be you couldn't find her anywhere, always on the go. Now you always know where she is." The patient added (tearfully): "Its been real bad. I can't even get out for groceries. I'm much more dependent on them."

The actual quantity or nature of the family's discussions about the illness is not known, since families were not observed during this time. Their stories, however, reveal uncertainty, confusion, delay and restraint, and backing away from confrontation with the illness until the patient was essentially housebound and in constant pain.

Patients and family were often isolated in their developing awareness and accommodation preceding the hospitalization. As one wife said:

He's not a complainer. We went on a cruise last year. He wouldn't dance. I kept asking him to. He would go out and dance a little and then stop. He finally said that it was because it hurt too much.

This remark represents a point of clarification, a coming together toward acknowledgement, or confrontation with the illness for this couple. It was not that she did not know about the illness until that moment, since the same family said the symptoms were present and had been building for ten years. In addition, it was more than a year after this discussion that treatment was finally sought.

The consequences of this isolation are described by another wife: "Its been a very difficult time, a great strain." She broke a thumb, (she was wearing a splint the evening of her husband's admission to the hospital). Asked to describe how the developing illness had affected their lives, she said: "Our whole life went downhill, we couldn't live normally. We haven't been anywhere, haven't been out in ages." When the patient interjected: "We went out just the other night," she responded:

Oh, that was just a movie. We really don't go anywhere. He doesn't walk, can't walk, and doesn't like to be with people like this. I went to China last winter, I go out occasionally, but I don't like to leave him alone. I want to get around again, so does he.

When the patient left the room to have an X-ray, his wife talked about his angry outburst with one of the interns:

He really exploded. He is under such strain, he's been so nervous, and we haven't talked about this at all since the surgery was postponed, for the last two months. He doesn't want to. He has even cried.

She too, became tearful at this point.

Conditions of Accommodation

The nature of the disease and its development may contribute to accommodation. Non-traumatic vascular disease has a slow and insidious progression. There are no visible signs until the disease is quite advanced or unless it presents as an acute ischemia. Sometimes, as with "silent" aneurysms, there are no symptoms that are discovered on examination for other circulatory problems or on routine physical examination. The patients in the study who had abdominal aortic aneurysm repairs all had other symptoms of the disease, such as severe claudication or previous myocardial infarction. The length of time between the first (noticed) symptoms of disease and the hospitalization ranged from six months to ten years for this study sample.

The aneurysm patients, three of whom accounted for the shorter time span between first symptoms, or first knowledge of their illness and surgery, provide a contrast group in terms of alarm, another condition of the family's response to the illness. One patient, with a thrombosed popliteal aneurysm, had sudden, alarming symptoms of severe pain and ischemia which motivated an immediate search for treatment. His search for treatment took several months, but his was the shortest "lag time" between symptoms and treatment. Later in the study he acknowledged that in retrospect he had had some vague, intermittent leg discomfort during the year preceding the acute episode, which he ignored.

Two patients with abdominal aortic aneurysms were on an "aneurysm watch" for approximately one month before surgery for different reasons. The patient and family were advised of the grave nature of their problem and signs and symptoms of rupture or pending rupture for which they should be alert. The family was vividly involved. The wife of one remembered:

We waited one month from discovery to surgery. They said how dangerous it was-- he needed a specialist for the surgery, our local doctor said it was beyond him. We called the medical center, and were told that all the surgeons would be away for a conference, and the one not going was booked solid, they couldn't schedule us. We called another center for vascular surgery, in Texas, but then found out that our insurance wouldn't cover it, so we waited. [What was that like?] We were very anxious, we did a lot of praying. Our friends, our neighbors, everybody prayed. They said to watch out for sudden sharp pain or loss of consciousness, but that by then it would probably be too late. We made it, though.

In the other case, the wife said:

When they sent him home to recover from the heart surgery they said to watch out for a stomach ache. The doctor said, 'You go home, but if you get a belly ache, you get your ass in here, don't fool around.' But we didn't have that. He started to complain of pain in his back, and he looked like he was having trouble breathing to me. I slept with him that night. I could tell he wasn't right. That morning, I brought some water and a wash cloth, gave him a bath, and said, "We're going in, and I don't want no back talk. And that was that. The doctor said a stomach ache, but I figured everybody's fixed different. I was right.

Another patient's abdominal aortic aneurysm was found on a preoperative arteriogram for scheduled femoral and popliteal artery angioplasty. He was kept in the hospital over the weekend and operated on on Monday morning. Three days post operatively his wife said she wasn't convinced that he needed the surgery, since he had never had any symptoms of that problem. His legs she understood, but not "this other thing." (She also asked, in the same interview, "What's an aorta?")

She had not been included in any of the discussions or decision making prior to the surgery. Her husband had a drawing on a napkin, which he showed her, but she said she didn't understand it too well. She was not a part of the fast-paced events, and was shocked by the extent, or seriousness of the procedure, by how sick her husband appeared after the surgery and that he was kept in the special care unit for four days.

The last of the aneurysm patients had a subclavian aneurysm which was discovered on routine chest X-ray. His wife described a well organized, methodical process of finding out what was wrong, what to do, who to do it, when and where, and a "lets get it done" approach, without worry because they knew that they were in God's hands and trusted that everything would turn out fine."

The confusion, false steps, and circuitous pathways to an accurate diagnosis and the proper treatment also contributed to uncertainty and, possibly, to the family's responses during this phase for some families. Two patients (including the patient with the thrombosed popliteal aneurysm) first sought treatment from orthopedists:

It started six months ago--did I tell you? We first went to an orthopedic surgeon. He gave him two cortisone shots in his spine. He didn't know what he was talking about, but who could have guessed that? Then he woke up with a white foot and blue toes, couldn't walk across the room. At first, his leg would hurt when he walked, and then it would stop hurting. We play golf and walk a lot. Then we saw a vascular specialist and he sent us here for arteriography. We came in for the surgery as soon as it could be scheduled; we wanted this taken care of.

Another patient, with severe aortic-iliac occlusive disease said:

The problem was going on for some time. My doctor said he wouldn't touch me with a ten-foot pole, that my chances were very slim. I asked him, what happens then? He said, 'I watch you, and then I take your legs off.' I said 'the hell with that, and with you if that's all you can do.'

I waited a few months, then it dawned on me to see my heart doctor. That same day he sent me to see Dr. S (vascular surgeon). So I went, I had an arteriogram. I was alone. I waited in the lobby. He came to tell me that it wasn't too bad, that he could operate, talked with me about the two arteries to my kidneys, and why the balloon thing wouldn't work. I had to go to Louisiana, so I went. Then B. (her daughter) and I went to talk with the doctor, and I talked with my heart doctor to see how it sounded. I knew I couldn't live with it, I would lose my legs, and if it's going to be done, let's do it while I'm strong.

Another patient had an initial diagnosis of cancer from a doctor near his camp, where he noticed a sudden increase in his difficulty walking. Later, back home, he talked over his symptoms with some friends at his club, who said that it sounded like something else--poor circulation--and they recommended a vascular surgeon. He consulted the surgeon, got a diagnosis, but waited for almost two years before undergoing surgery.

After complaining of extreme pain with exercise at her senior center, and being told to "try harder", a patient asked her psychiatrist what to do. She said: "I'm kind of mousey. I was afraid to tell Dr. J. (her internist) about the legs." The psychiatrist encouraged her to seek treatment.

The family's experience with the patient's health history and behavior is another condition which contributed to their response. This patient's husband said, "I didn't believe her, she's always complaining."

Another patient, with a femoral artery occlusion, said he had noticed a difference in his right and left feet for years--one was thinner and had no hair, the nails were drier. His leg pain got worse and worse, but it was his podiatrist who recommended that he get an arteriogram.

The most direct route to surgery was in the case of the "veterans," those patients with diabetes, and/or those with known coronary artery disease, or with previous vascular surgeries. These patients were already under physician's care for a known disease process, which avoided the others' confusion and delay.

Family activities and involvement increased dramatically shortly before admission. Vague symptoms became pressing and constant, and the disability impinged on the family's life routines, demanding greater and greater sacrifices until treatment was finally sought. It was remarkable in the case of the advancing arteriosclerotic, symptomatic disease how long families and patients tolerated and made allowances for the illness and disability in their lives before seeking treatment.

Families in no case took unilateral action to seek professional consultation on the patient's behalf. Family members were brought into the trajectory for practical, emotionally supportive, and evaluative assistance by the patient, or in negotiated partnership with the patient. "P. was included in the meeting." [How did that happen, did the doctor suggest that?] "No, I engineered for P. to come before the surgery. The doctor drew pictures for him."

Although family members were welcomed and included by physicians when they were present, families did not report instances in which they were explicitly invited by physicians to participate in the process of learning about the problem or decision making except in the one case where the decision to have surgery was sudden and urgent. The patients themselves brought their spouses or other family members with them, when they did not go alone into the consulting office (which was the more usual case).

Family Work of Accommodation

Health work. During this phase, the family health work consisted of watching (observing, interpreting the signs and symptoms of the patient's developing disease) and waiting (deciding what was important,

what could be ignored, when to say something, when not to). Health work, if it can be called that during this phase, consisted of accommodating and/or compensating for the patient's increasing disability, allowing for the extra time it took the patient to move, and easing their burden of daily tasks. In retrospect, families described the "terrible time" the patient had walking, the "slow shuffling", and the deterioration in the quality of family life, but they did not actively intervene.

Family health history and culture, closely tied to relational work and psychological work, influenced health work. As one patient said: "There are so many hypochondriacs in my family. Things get worse if you pay attention to them." The husband's comment that his wife was always complaining is another example. A Hispanic spouse remarked that the illness and treatment were between his wife and the physician. He felt that he had no right or reason to participate. Age alone did not seem to make a difference in the family's responses during accommodation. In the context of pre-existing illness, the leadership of the one seeking treatment was even more pronounced.

The way the problem presented itself, slowly with no "alarm bell" or in the context of alarm and grave danger, also influenced the family's health work. The more alarm, the more active and vigilant the family. In only one (non-emergency) case did the wife confront the patient directly and insist that he get treatment, and that was when she returned from a trip and saw a dramatic deterioration in his condition. All others followed the patient's lead.

Relational work. The family's involvement varied by family role, an expression of relational work as it affected accommodation. The most

actively involved were spouses, followed by (adult) children, then siblings. Individual variation within family relationships dictated behavior beyond family role.

Access to information, part of knowledge work, was generally more limited when the patient was a parent. Parents took the lead and maintained control of their health care. This control was compounded when the parent was a veteran.

In the admission interview, a "veteran" (diabetic) widowed mother said that her two "boys", 24 and 18, would not be coming to the hospital for four days, when she expected to be back on the regular care floor. When she was asked why not, she responded: "I decided that nobody's comin' in until after the surgery. I don't want them to see me with all those tubes. I don't want them to worry, I'll be all right."

A daughter described her mother's approach: "I only know what she tells me, and she only tells me what she wants me to know." The patient's cousin, present for the admission interview added: "We can see behind the front, we know there's more, but if we confront her, it leads to tears. It's a real challenge, you have to tread carefully." A father (who lived alone) called his son to tell him that he was in the hospital and would be having surgery the next morning.

Siblings were relied on for practical and emotional support when they were the only family available, but not for sharing decision-making responsibility. Siblings maintained limits for their role. The sister and brother-in-law of one patient were asked the morning of surgery what their greatest concern was at that time. They said a family reunion with 36 people scheduled for this weekend at their country house. They hoped that things would go smoothly for the patient so that they could

take off, but "We don't mind taking care of her. She stayed with us the last time. We are retired, and this is something we have the time to do."

The other sibling, a brother, brought his sister to the hospital and visited regularly during the hospitalization, but retreated, limiting his involvement to phone calls and occasional visits when the mother arrived from another state to be with her daughter after discharge.

Some spouses were more, others less, assertive or actively involved. Spouses used their normal patterns of interaction and their knowledge of the patient to take their direction for how they managed/dealt with the situation. Some couples seemed to have more of a partnership than others. They told their stories with "we" instead of "I" and "he." "We're alone, just the two of us. We solve problems together, for 42 years now, and we're pretty good at it."

These partners described philosophies of "getting this thing taken care of as soon as possible", learning all about the problem, getting as much information as possible. "I'm the kind of person who likes to know, good or bad, so that I can cope with it, R. too." "We worked as a team, generally, we took it one step at a time."

These partners displayed a mutuality, a reciprocity, an awareness for the other and what they must be feeling and thinking. In the hospital, the patient "took care" of his or her spouse, i.e., limiting the visiting, directing and participating in home work decisions and problems.

These features were not absent from other, less mutual pairs, but it was a prominent feature of the partners. Partnerships sometimes

evolved during the course of the illness and treatment. For example, in one recently married couple in the study, the husband (who was the patient) was completely in charge of events and decisions at first, directing his wife and working hard to keep her from becoming overwhelmed. When asked at the home visit what he had learned from the experience of hospitalization and recovery thus far, he said: "Well, that I have somebody here. She is capable. She is strong. This is the first time we had a test like this in our marriage. I have somebody that I can count on."

This reciprocation or concern for the family care partner tended to work well and signal an effective problem solving relationship for most families and couples. When it was expressed in a very rigid or exaggerated way, as was the case with three mothers in the study, it seemed to backfire. One of these said, on the evening of admission while crying, "I am too independent. I told them not to come tomorrow. They shouldn't miss work. Ain't nothing they can do for me anyhow. I been independent all my life."

Three husbands described their role in decision making and helping their spouses not to feel "hustled" or rushed. All of these couples described themselves as close and mutually dependent. The circumstances for all three were that the severity of the diagnosis was shocking. The spouses had to do some rapid knowledge work to learn, evaluate and be convinced of the need for the surgery. In one case the husband recounted:

Our internist recommended this vascular surgeon for the problem with walking. He wanted angio and surgery the same day. I thought, wait a damn minute, we're being hustled. We asked around, took our X-rays to Dr. E. (at the medical center) for a second opinion. He said definitely she needed the surgery, and he had an opening. We thought about the advantages of the medical center over our local hospital even though it was farther from home, and we took it.

In another case, the wife (patient) and the husband were shocked by the news that she would need major surgery. She said she felt like the surgery was being pushed on her. The surgeons told her to call her husband, who reacted with anger. He was in the car repair business and related the situation to his work:

We came in with one estimate, and now there's another, I feel ripped off. Isn't there any other way to treat this, diet, medication? You can't tell me it developed over time, she's a waitress and she's on her legs a lot, she'd have known about it. I don't believe in rushing her."

Another husband described his role:

She didn't want to make the decision without me there. F. is not at ease without me. I'm always hesitant. Doctors are not Gods. I'm not so thrilled about the way doctors recommend things you don't need, they are just experimenting. [Do you think so in this case?] No, she needed this one, I think. I didn't think so at first.

They have to make a living too. She's had a lot of care, doctors, taken a lot of medications over the years. I just hope it's all necessary.

Knowledge work. The family's knowledge work of gathering information about the problem was for the most part not evident until professional consultation, and even then it was "opportunistic", rather than planned or self-initiated. Only one family member, a daughter, asked to accompany her mother on her second visit to the surgeon, specifically to learn about the problem and what he was planning to do.

Home work. Home work during this stage was the work of adjusting family routines to the increasing disability, juggling and making arrangements, sacrificing normal and pleasurable family routines. Asked how the family managed the mother's increasing disability, the daughter replied, "K. (the patient's granddaughter) was the one. She is the only one who doesn't work, so she stayed with her, stopped in, got her

everything she needed. She was the main one." A wife said: "He never took me anywhere, he couldn't drive too well, so we never went out."

Nearer to the time of admission, home work consisted of preparing the house for being away, when the couple had to travel some distance to the hospital. No one said they asked neighbors or friends to look after the house: "The place is pretty much on automatic pilot, but they are certainly available if we need something."

When the wife was the patient, in two instances she did advance shopping and cooking for her husband: "stocking up". Others' husbands routinely did the cooking for the household or shared the cooking and shopping responsibilities and one was an urgent, unexpected admission.

Juggling arrangements to transport and accompany the patient on trips to the doctor with work schedules was other homework when the treatment seeking activity began. For example, a Hispanic family arranged family and work schedules so that the oldest son, who spoke the most fluent English, could come to the consultation with the surgeon.

The Black American families in the study all had multiple family members who could be called upon to share in the home work, the transportation, accompanying the patient to doctor's offices: sisters, cousins, adult children all shared this work, just as they shared the work of adjusting the family routines to accommodate the patient's disability. Neither adult children nor extended family or friends were asked to assist with home work tasks for the majority of the study families, however. As one patient's wife stated: "We have two kids, but I don't include them now as we discuss family things. Our daughter lives in [city nearby]. She's medically savvy, but she's just no good in a crisis."

Psychological work. The psychological work of identity management and performance control must be inferred from the other family activities and remarks, and was, like knowledge work, closely tied to family relationships. Certainly, it involved "keeping cool," i.e., showing emotional restraint in the face of distress and uncertainty. As one wife stated: "My husband is scared, real nervous about this (the surgery), but hasn't expressed himself. He spends most of the time trying to get me to believe everything gonna be alright."

The older son of a patient was restrained both by his mother and by practical difficulties in his communication with the surgeon. He was distressed by this, and said that he felt helpless to fulfill his responsibilities as the oldest son in the family for his widowed mother, but he did not pursue it.

Some family guilt was expressed as a result of not taking earlier action in relation to the illness. As one husband said: "I didn't believe her, she's always complaining." His wife said, "I wish I had been more bitchy."

Psychological work was the work of restraint and control, in order not to usurp the patient's own agency unless and until they felt it absolutely necessary. For those who did intervene, the work was also to anticipate and manage the patient's reaction to their efforts. For some, it involved managing the frightening "aneurysm watch", and being ready to take action, but not panicking.

The psychological work of anticipating the patient's response, or coping with uncertainty was somewhat mitigated for the families who were already under care, whose condition arose from a preexisting and known disease. The patient was "in good hands", the family had less-felt

responsibility, although, as in the son's situation already described, he wanted to play more of a part and felt excluded and helpless.

Summary

Until the events immediately preceding the patient's admission to the hospital, most families exercised restraint, following the lead of the patient in their response to the developing disease, and in their sometimes elaborate accommodation of their lives to the advancing disease. The exceptions to this general finding were those operating under conditions of greater alarm, or urgency: the aneurysm patients' families, who were more active, involved and vigilant. These families were also better informed (at least about the imminent danger). Lack of knowledge and ambiguity, a product of peripheral vascular disease's insidious progression and its misdiagnosis, may also have contributed to the family's hesitation or lack of clear mandate to take action until the symptoms were intolerable for the patient.

The most active and involved family members were spouses, and of the spouses, those with the more open partnerships. Families were not actively included at this time of diagnosis by health professionals. They were, however, welcomed and included when the patient brought them into the process.

Relational work dominated this phase, as families sought to maintain family stability and equilibrium, and avoid conflict in family relationships. Out of this accommodation phase, the family emerged as bystanders, successful at containing the crisis (avoiding family disruption) but largely unprepared for the events of hospitalization. Even the more vigilant and those with more open partnerships were

constrained to some extent by the health care conditions and their own psychological needs to maintain family equilibrium in their knowledge work, and remained largely uninformed at the time of admission about the nature of the illness that required surgery.

In this period of developing illness until the hospital admission, containment explained the family's accommodative attitudes and behaviors in response to the illness's advancing intrusion into the family's life.

Confrontation

The phase of confrontation encompasses primarily the time period of the patient's hospitalization. A few families had confronted the serious nature of the problem earlier, during the phase of accommodation, and particularly at the time of certification, when the patient was told that there was a problem serious enough to warrant immediate surgical intervention. It was during the hospitalization, however, that most families were first confronted with the realities and the seriousness of the patient's health problem.

During the hospitalization the family experienced the peak of their own and the patient's distress as they lived through the surgery and early post operative period. They saw the patient for the first time as a patient. The day of surgery, the waiting period during the surgery and the first sight of the patient after the surgery were identified by all families as the "worst" times or moments during the whole process. The family disruption, staved off by accommodation, now began for all.

Admission to the Hospital

By admission the family was clearly involved in the patient's care, if only in terms of their adjustment to the changes in home routines and activities associated with the patient's departure for the hospital. Activities such as transporting and accompanying their relative to the hospital, packing, closing the house or apartment, arranging family and work schedules to fit with the hospital's and patient care, and taking over the patient's roles and functions in the family created family involvement.

Some had more notice of admission, some less. (All but two surgeries were designated as elective). The less notice, the more family "scrambling" (in the words of one family member) to get the patient to the hospital and take care of the family affairs and routines. One patient was notified of Medicare clearance for her surgery at 2 P.M. and was admitted by 3 P.M. the same day. She left dinner cooking when she took off for the hospital, accompanied by her daughter. After getting her mother settled, the daughter left again to turn off the stove, throw out the burned pot, pick up her mother's glasses and address book.

Precipitous admissions were more distressing when the family and the patient are surprised by the need for surgery. The husband of a young (45-year-old) patient became very angry and protested his wife's admission and the need for the surgery and accused the doctors of trying to "rip him off". He was called to the hospital by the patient to help her to decide and was so distressed himself that he was not much help; in fact the patient ended up comforting him. (They did not have health insurance, the only family in the study without it, or a health plan

that covered the major expense of the surgery and hospitalization). He said, "How am I going to get along without you tonight? How am I going to get along without you this week?" The wife of a patient who underwent abdominal aortic aneurysm repair after admission for angioplasty procedure was not convinced that he really needed the surgery until a week later. Looking back, another patient describes "the thing she was most pleased about, or proudest of," in the whole process was her insistence on waiting a couple of weeks before the surgery, so that she could be prepared.

Veterans' families more often "dropped off" their relatives, or the patients arrived and were admitted on their own. Recruits brought more vigilant and anxious family with them. Veteran patients were more in charge and controlling of the admission and the family's involvement. One veteran parent, previously described, insisted on coming to the hospital alone and not being visited for the first four days.

Hospitalization as Jurisdictional Change

Admission of the patient to the hospital represented a major jurisdictional change for families. They had to "turn the patient over" to the "authorities", the doctors and the nurses. Some did so with relief that now something would be done to alleviate the problem, others were more anxious and wary observers of the unfamiliar milieu.

Role confusion and lack of orientation. The family experienced role confusion. There were no role or task guidelines for family in the hospital. Except for the "veterans", who had some experience and came to the hospital with some prior knowledge and expectations, families had to invent their role as they went along. (The veterans' expectations

served some helpful, some obstructive and confusing purposes, as will be elaborated in this section).

The physical environment accommodated them with, perhaps, a chair, or a waiting room. (The newest of the three hospitals had a comfortable family room on the unit). Sometimes the family received a tour of the new environment, most of the time they did not. Should they use the patient's bathroom? Can they share the patient's food? One patient, a diabetic, complained of hunger after her admission and told her granddaughter to go get her something to eat. The granddaughter went to the nurse's desk, waited patiently for someone to look up and acknowledge her presence and to listen to her request. Some minutes later, when the nurse looked up from her work, the granddaughter was told that as yet there were no doctors orders, so they could not order food for the patient. She went back to tell her grandmother, who sent her down to the cafeteria to get her some cookies and milk: "Lots of cookies," she said.

The patient was seen by many different staff members the evening of admission. At one university medical center, the investigator waited in the hallway, in line with four others who were waiting to see the newly admitted patient. The husband was also standing in the hallway, waiting to be able to go back and see his wife again. He seemed relieved to be able to walk down the hall and talk with the researcher.

There were few guidelines for communicating with staff and especially with the surgeons. Most opportunities for speaking with the physicians were opportunistic and dependent upon the family's assertiveness in the interaction, which was usually hurried. Families were grateful to have some guidelines, some orientation to their role

and the strange environment. The absence of these guidelines was disorienting and frustrating. Here, veteranship did not seem to help if the environment was new or unfamiliar, or not as expected. The following are comments from families on the subject.

One thing that made a big difference was that you told us about the CVS [researcher had mentioned that the patient may be admitted to CVS, a special care unit, after surgery]. Nobody said anything about it. She was in CVS, and I called right in. The only thing they told us on the unit was about the blackboard. [Where families put their phone numbers or location in the hospital]. Most problems are from a lack of considering what needs are, not helping to anticipate. I prepare myself by trying to anticipate. It should not be up to the family or the patient to ask. Mother is more of a street fighter than I. You have to keep after people and be persistent. I am more discreet. It's only one day's experience; but, and they told us about the blackboard, mentioned the solarium, but the impression was: 'Hurry and go away', a chilling effect, inhibiting questions.

Orientation mechanisms were present. One site had a "family blackboard" so that the family could leave notice of their whereabouts in or out of hospital to assist staff to locate them. Not all families knew about this mechanism, however. One patient's husband could neither read nor write.

Nurses were occasionally observed talking with families and patients on the evening of admission, and providing some preoperative teaching and guidance. The families, however, were not aware of this as such, and most did not receive this orientation in a systematic way that could later be identified as particularly helpful.

Another wife (a veteran) expressed her wish not to have to ask for assistance. "Why do I have to ask for everything? The last time, [for coronary bypass surgery at another hospital] they told us everything; [this time] we didn't even know how to find the bathroom, where anything is."

The absence of expected orientation was frustrating and emotionally painful. In a telephone call to arrange to meet with the wife of a patient, the researcher asked what time will she would be coming in to the hospital. She answered:

Oh, I don't know. What time is the surgery, or, what is it? [Angioplasty] Yeah, that's it, I have to see it to remember, don't understand much about it. I waited all day, for four hours for him yesterday when they took him down, and then I missed him coming back. They snuck him in. I went home.

When they met the next day the patient was having his angioplasty and the wife was waiting. The researcher asked if she might like to go for a walk, or would she rather stay there to wait? "Go for a walk, I'm tired of sittin'". The researcher stopped by the nurse's station to ask when the patient was expected to return to the unit, so that his wife would not miss him once again. The nurse called the radiology operating room, and told us that he would not be back for at least another hour, and that he was doing fine, things were going well. We left for a walk.

The patient's wife would not have asked for that information. She said that she wouldn't have thought to do that. And, perhaps the nurse would not have called the OR if the wife had asked her the same question without the researcher. The family was required to pick up clues, patch things together for themselves, and cope with a tremendous amount of uncertainty throughout the hospitalization. Some seemed better at these tasks than others.

Families may have felt that they had the right to question, to monitor, to understand what was happening; and they say they did when they were asked about it in the interviews. They rarely exercised this right, however. They watched and waited, picked up cues from the situation, and gathered information opportunistically. They seemed to

be without the necessary skills, experience or background knowledge to formulate questions and to arrange to have these answered. This pattern continued throughout the hospitalization, setting the tone of the family's behavior and responses during recovery.

Configuring. "Configuring" was an in vivo analytic code for the family's opportunistic, pieced together, incidental information gathering by which they navigated through the experience of the hospitalization. One husband used the word to describe how he figured things out; specifically, why he did not ask nurses any questions. "From what I could configure, nurses are so careful because they can't stick their neck out, they are not in charge"

The daughter of a patient said:

I feel real good, she's doing real well. [Yes, she is, but I'm curious how you know that.] The doctors came while I was there, I just kind of listened so I figured out from what they said. [What did they say?] Something about her medication, that they are cutting down her medication, and that she'll probably eat tomorrow, that she's doing well.

A wife noticed the dinner tray at her husband's bedside when she returned from a trip to the bathroom. She said she was starving, and looked longingly at the food. She asked one of the nurses if she could eat the supper, which was getting cold. The nurse said. "No, he's hungry. They called from the OR to have it ready for him. He's alert, fine, and he'll be here at 7." Thus, incidentally, she learned a great deal about the patient and his schedule.

The family was proud of their configuring. "Doctors were very nice, but they downgraded the seriousness of it. There was nobody around to ask questions, nobody to ask. Nobody is smarter than I am anyway."

In another interview a family member said:

During the time that she was in the hospital I didn't get the chance to talk to the doctor. I had to piece together the facts, just out of observation. I found out that I was right, when I finally did get the chance to ask.

The Day of the Surgery. The only consistent family-physician contact during hospitalization was the doctor's visit to the waiting room after surgery. Only 14 of the 20 families in the study had this contact, however, for a variety of reasons, e.g., the family member could not be located, or the surgeon had another emergency surgery.

These contacts were "peak experiences" for most families. Most were highly anxious by the time the physician arrived and not prepared, emotionally or mentally, to ask questions. These families had waited without information or contact with health professionals from six to twenty-two hours after the patient's anticipated time of return. Even when the time was given as a rough estimate--"the surgery takes about three hours, but don't be surprised if it takes a little longer"--the family counted on the three hours, and began to worry after that. One husband's remarks describe the experience of most:

That day, the day of the surgery, I didn't hear anything until 3:00. I started waiting about 7 A.M. I expected to hear about noon. It was awful. Three hours without knowing. You always think that something can go wrong. When he finally came to talk to me, I just held my head in my two hands and said, 'Oh, I hope everything's alright.' But when I got the news,, well, all those hours they went away, and it didn't matter. I heard good news and that all.

[Did you ask the doctor any questions then?] "No, I didn't ask him anything, no. My son wanted me to call while we were waiting. You want to and you don't want to, you don't want to disturb, you know?"

The wife of a patient who underwent an abdominal aneurysm repair said, "I couldn't get any information while he was down there. I asked at the nurse's station, and was told that they were too busy to call and

see how he was doing. I just paced and worried." Earlier, she received a call to come down to the OR floor.

They called me, said the doctor wants to see you. They had his wedding ring for me. My imagination went wild. People in the business [she was an X-ray technician] worry more, too. We know all that can go wrong. I ran into L. here [the CNS nurse] and she phoned, and told me everything was going fine. I had told her I was considering going out of my mind. She's a blessing.

This informant was unique in expressing her anger. Most were more careful, and more forgiving. Even this woman's complaint was followed by an apology: "I'm so sorry to complain, the nurses work so hard, twelve hour shifts, I think--good for patients, I guess, but maybe there's someone else, an ancillary worker, who could communicate with us?" Her remark to the CNS nurse was indirect.

The fact that the nurse understood her indirect request and was responsive was considered a "blessing." (Another family also made the suggestion that staff use a "go-between" worker, one who could move freely between intensive care environments and family waiting rooms to communicate with the family.)

The experiences of the husband of a patient undergoing an aorto-femoral bypass graft illustrates both the comfort when things go as planned and expected on the day of the surgery and the acute discomfort when they do not, from the family's perspective. In this case, the husband, an engineer, was more active, assertive and vigilant than many of the family members in the study. On the day of surgery, as the researcher was asking the (special care unit) staff for news of the patient's progress and condition (she had not yet come up from surgery, at 3:15 P.M.), the husband walked into the CVS to do the same. The nurse introduced herself to the patient's husband, and said that she

would be taking care of his wife tonight, that she (the patient) was in the recovery room, and that she was expected in about an hour, at 4:15 P.M. He said in an interview shortly afterwards that this was the "worst time, the rest would be easy."

The surgeon had called him at work: "Right on time--ten minutes past one, he said he'd call about one o'clock--to say that everything had gone as expected, and that she was in recovery--can't do better than that." At 4:10 the husband and researcher returned to the special care unit, and the patient wasn't there. ("Not home yet," he said). When the researcher checked again at 5:00, she was still not there. Her husband had checked several times: "They said not to worry, so of course, I'm not going to," he said.

The difference in the staff's and family's time perception was dramatic. When asked where the patient was, the nurse said, "She's not back yet, but it's only a half hour or so past the time we said she'd be here." The patient's husband was called later that evening, about 8:45. He said she got back about 6:30. He said, "The surgeon's assistant stopped me in my wanderings to tell me she was back, it was a pretty long wait. I'm getting to know my way around, I must have walked eight miles today."

Discharges were often precipitous, and the family, once again, "scrambled" to manage. A wife, whose husband was discharged on the sixth post operative day after an AFBG said:

I was surprised that they sent him home so soon. He was just beginning to feel better. The booklet said ten days, I counted on that. [Did you say anything, ask about it?] I wasn't there when the doctor said he could go. What could I say? I really thought the earliest would be the middle of the week. Work was a real problem. Basically, I was ready to take time off as of Wednesday. [So, how did you manage?] My

daughter-in-law was there, and I thought to myself, nothing terrible is going to happen. I had loads of questions, though, and none of them was answered. How it happened was Friday night one of the doctors said, 'Are you anxious to get out of here?' So he said 'Sure'. Then the doctor said, 'At some point you can get rest at home too, rest at home can be as helpful as rest here.' The vascular book says 10-15 days. That was my timetable. It needs to be revised. It also says he should not sit erect, which concerned me. He was doing that there, and now.

In a later interview, she said:

I wish they could have given me advance notice. I was not prepared. I said, 'Oh, my God, oh no.' I felt guilty about feeling that way, I couldn't be there for him the way that I wanted to be. And, there was no instruction about activity. He minimizes everything, so if the doctor said anything else, I couldn't tell.

Another patient's daughter said:

It seemed like the middle of the night. The doctor came in, he'd been in surgery. I was there, getting ready to leave, and he asked me how I would feel about tomorrow for her to come home. I said fine. He said to watch her, if she starts to swell up or if her stomach protrude, and to make an appointment to come and see him. I had to scramble to make all the arrangements, cancel two appointments, clean up.

Discharge instructions were patient, not family, focused. Most instructions were stated in general terms, i.e., "If there is a discharge, call the doctor." (In the case of this advice, the patient came to the hospital emergency room because she had a vaginal discharge.) Instruction about taking pedal pulses was mentioned by only one wife who said that the responsibility made her nervous. Recovery care instructions were included on the last page of an information booklet given to patients at one of the sites, but most families had not read these pages.

On the morning of discharge, an intern said to the patient: "I'm here to remove your stitches so you can get out of here." The patient said, "Is that all? Just remove my stitches?" "Yes," the intern

replied. The patient said: "There's a lot more that needs to be done before I'm ready to go." There was no comment from the young doctor. After the stitches were removed the intern left. The researcher asked, "What else needs to be done"? The patient said he needed to talk with the doctor about the use of anticholesterol drugs, and that he wished to see his nephrologist before he went home. The surgeon visited the patient sometime afterward. He said: "All is well, the surgery is good, and you should have no problems, there is nothing more to do in the hospital, you should make an appointment to see me."

Medications were reviewed as routine discharge nursing care. Visit by a dietician before discharge (or anytime during the hospitalization) occurred in three cases. At one site there was a regularly scheduled "discharge meeting" of the family, the patient and the nurse employed by the surgical practice group. In the other sites discharge instruction did not seem to happen in any regular sense. Patients and family members could recall statements such as "Okay to shower in three days," and "take it easy for the first week." One doctor said: "I'll make you a bet that in two weeks you're going to tell me that I didn't tell you that it was going to swell that much." The patient was rather confused by that. Another daughter of a patient said, "I'm not so clear on her activity, I guess whatever she feels like. The doctor said nothing, but is driving OK?"

Family Work

Knowledge work was the dominant and critical family activity during confrontation. Some description of the family's work to gather information has been given, in the discussions of the inconsistent family orientation to hospital routines and families' "configuring".

The construction of a definition of the patient's illness and treatment and its implications for the family was ongoing, major knowledge work begun largely in the circumstances and experiences of hospitalization. As patients and families were followed throughout the hospitalization, there was a remarkable absence of reference to the notion of disease per se; the disease process, the diagnosis of peripheral vascular disease, or its prognosis. The illness was represented in the patients' and families' remarks as a structural problem, a blockage, stenosis, a bulge, an occlusion, but not as the product, manifestation, or symptom of a systemic disease. This bounded, particularized definition seemed to be generally supported, or at least not interrupted or challenged* by the care providers in their interactions with patients and family.

Patients and family members asked important questions during research interviews, e.g., "What's an aorta?" "Do you know what causes this artery blockage?" A striking feature was that neither the patients nor the family members pursued these questions with their physicians or even with the researcher.

On the morning of discharge a wife of a patient was asked what was her understanding of the cause of her husband's aneurysm. She said (accurately), "high blood pressure and smoking," but then asked, "but

* Asked if his patients could be approached to participate in the study, one surgeon expressed concern that the investigator might scare the patients, make them more anxious by talking with them. He said:

The heart surgery is more mystical, lots of stress, the heart is stopped for a while, even though the surgical risk is just as great with the major vascular surgeries. They think of it as just like any ordinary surgery, fixing a tube, or a colon. Just use your common sense not to alarm them.

why there, in that spot, and why now?" She was encouraged to ask the surgeon. In subsequent interviews, she had not done so.

A physician's note in this same patient's chart stated: "Will evaluate for other possible aneurysms." The morning of discharge the patient was in the ultrasound lab, "getting checked out," according to his wife. Asked what they were checking, she answered, "the leg they operated on."

The evening before her surgery to reconstruct her renal artery another patient said: "What causes this stenosis? I have been so careful about my diet, for years, no fat, no butter." Her diagnosis was renal artery fibrosis, an arterial disease which is not related to diet. The researcher asked this patient if she had spoken with her doctor about the cause of her disease. She said "No, not yet, I will."

It seemed that both the family and the patient moved in and out of a process of developing realization of the full implications of the vascular surgery. When asked directly, many displayed more or less accurate, even if incomplete, knowledge of factors associated with the development of PVD but were not active seekers of information to fill knowledge voids and inaccuracies. There seemed to be a "stubbing off" of concerns, an opening and a closing, a tentative exploration, then a turning away.

The family's definition was a product of partial, incomplete knowledge, pieced together, forays and retreats from knowing. When asked why they had not or did not explore their questions with their physicians they had a variety of answers. "I am asking you." "I don't want to feel like a dumbbell." "They don't know anything anyway." "I will look it up in the library, read about it, I just haven't yet."

There seemed to be several explanations for this finding. One was that in the hospital the patient and the family were focused on the surgery itself, which took all of their attention. Another was that sufficient opportunity to explore concerns or an invitation to discuss their illness and the implications of surgery was not presented.

Care providers were not specifically interviewed for this study. This analysis is based on data provided by patients and family interviews and situational observations. Doubtless, there was discussion of disease process with physicians and other clinicians prior to the hospitalization and during the hospitalization. There was, however, no systematic provision for the patient and the family to discuss the illness or the surgical prognosis during hospitalization. The exception was one study site in which a discharge conference with a nurse employed by the cardiovascular surgical group was provided as part of the routine care. As she stated, however, "Sometimes I don't make it. We really pay more attention to the cardiac patients, but we try to sit down and talk with the vascular patients and their families too, to go over risk factors and recovery care."

Those who received this counseling acknowledged the implications of the surgical event to some degree and expressed less family conflict during home visits. In another case the surgeon exhorted the wife of a patient to work to prevent the progression of her husband's disease when he saw her in the waiting room after the surgery. In a post discharge interview this wife said:

The doctor talked with J. before, to change his life style. But when he came by after the surgery, he was definitive. He said that he could not do what he wanted, to just clean out the artery. The disease was more progressed. He had to do a bypass. He said it's very important that he doesn't smoke, and that he modifies his life style, change his diet. I've

modified my eating. The cardiologist said that he may be at risk of heart problems. He didn't say that as strong to J. What I felt was, why didn't he come on as strong with J.? Maybe he didn't want to get him discouraged.")

As this wife's remarks illustrate, the patient and the care partner had some knowledge of the disease and of risk factors. Incomplete knowledge, gathered separately and in piecemeal fashion resulted in family conflict rather than effective risk management after discharge.

The patient was the family's major source of information during hospitalization. The family was then at the patient's mercy and under his/her control. Family members were observed asking nurses the purpose of a procedure, the outcome of an assessment, like blood pressure, temperature, or where to find things, like extra blankets, but not "big things," like how to manage at home during recovery, or how to prevent the progression of the disease.

When asked if anyone had spoken with her about discharge and recovery care, the wife of one patient replied: "No, maybe they talked with R., though." She got up to look at her husband's yellow pad. "Hmm, it says, 'visit with MD for staples out next week, golf in two weeks, driving in three weeks.' They left this booklet."

She had not looked at it. The wife and researcher discussed some of the sections on recovery, normal incision care, gradual activity, risk factors and low fat, high protein diet. She said, "That means no bacon. I need that written out so he'll pay attention. He won't pay attention if I just say so."

This couple was one of the most active, vigilant partnerships in seeking treatment and getting information throughout the hospitalization. On the day of admission, the patient alerted the surgeon that his wife was coming and asked him to wait until she came to explain things.

She arrived a few minutes later. If the patient had not asked the doctors to wait, or if the wait had been too long, this important opportunity would not have taken place. The wife remarked: "I was late. He waited for me. I was so glad that he did, it was so helpful to hear all that." And,

The hospital is a totally foreign atmosphere, you don't want to ask questions. I didn't think it was going to be as big a deal as it was. A big surprise, shock to find the aneurysm. It wasn't until we were in the hospital that it was totally clear." The patient stated: "That first talk was beautiful, they did a hell of a job.

Even with this couple's teamwork, initiative and openness, there were important questions left unanswered. She was the one who had asked the investigator why the aneurysm appeared in that place and why now; she complained of not having the authority to say what he could or could not eat, and spoke of her hesitation to ask questions in the foreign atmosphere of the hospital.

Families constructed their own landmarks of progress or recovery. One couple interpreted the removal of the intravenous line as a major recovery landmark. When it was reinstated because the patient had a paralytic ileus, they were devastated. The patient became severely depressed. She wouldn't get out of bed, wouldn't open her eyes to speak to her husband. The husband had not asked the staff why the line had been started again. He asked the researcher:

Have you seen this before?" [Yes.] "Do they get better?" [Yes]. How long to get better? [Not very long for most people--what did the doctor say?] "When he came in to check her I left the room so he can feel more comfortable to examine her. She tell me that it's nothing to worry about, it happens sometimes."

Other knowledge work included planning for and anticipating events, scheduling and juggling multiple family tasks and responsibilities. An

example of the work of navigating events in the hospital on the day of surgery is this interview with the wife of a patient who was having an aortic aneurysm repair:

They told me to take a couple of hours to go shopping. I did, but I came back too soon. They called me at 3:00. Twice I heard my name before that, but it only sounded like it. [How is he doing?] "He's fine now. After I came in from shopping, I checked the information desk. They said he's in 455. I went up there. He wasn't there. The nurse said he'd be in the CPU. I went back down here (the lobby), waited for three hours. Then they called me, told me to see the doctor on the third floor, in the CPU. He said he was fine, the operation went well. [What did you do then?] "I came back here." [Have you seen him yet?] "No, I figured if I could'a come in he would'a said." [We can go up there to see him. Would you like to?] "Oh, yeah."

The researcher spoke with the CPU nurse, who said that the patient was stable, and to wait about a half hour and then she would come to the waiting room to bring the wife in.

[The nurse will come and get you, in about a half an hour. He's stable.] Yeah, good. I figured that. [Would you have come up here if I had not suggested that?] No, I'da gone home. I was just trying to reach my son on the phone when you came. [Do you wish you had?] No.

If there was intervention to assist families with these tasks, the families did not acknowledge it as such. Certainly, the nurse's advice to go out for a walk was an attempt to do so, but the wife spent four hours in the lobby of the hospital, and would not have seen her husband after his surgery if she had not been in a research project.

Most care events occurred without notice or very little notice, except the surgery itself. The patient's discharge was an example of the family-care environment interaction around event planning. Some anticipatory work on the part of the family about discharge was evident, but mostly in terms of the patient's personality, using their previous knowledge of their relationship as a guide, e.g., "I hope she won't be

too demanding, hold back too much," and "He's not going to do what I say."

The family seemed to be getting ready, preparing themselves for the struggle ahead after the discharge. For example

He's so tired. I wonder if he is going to recover. I don't believe his expectations will be met as far as what he will be able to do. [What have you been told about the recovery?] We haven't been told anything. Dr. S. is on vacation, and another doctor is covering for him. We haven't seen him yet. [Have you given any thought to how you will manage after discharge?] I will need someone to help when he gets home, someone big and strong, with authority.

Families were generally inhibited in their knowledge work by the almost exclusively patient focused care. They often remarked that they did not want to interfere or disturb anything in the situation. A few families made strategic plans to be present when the physician was, by asking the nurses when he or she was expected and waiting in the patient's room, sometimes until eleven o'clock at night.

There was not one instance of a family calling their physician during the patient's hospitalization, although one left a note for the surgeon, to which he forgot to respond and for which he later apologized.

One family member was found washing out her mother's commode. She said: "The potty chair has not been cleaned. Who is supposed to do that, the nurse or the housekeeper? It was so smelly in here, what if it is dirty when company comes?"

Intensive and special care nurses were most frequently mentioned as sources of information and as resources for the family. Family members mentioned these nurses by name in the interviews. In the field observations, the intensive care nurses were more spontaneous in providing orienting information to the family. They did not wait for

questions; they explained and described what was going on, how the family could reach them, where to stay when they were not with the patient. When they asked the family to leave, they always told them when they could return, and that someone would come and get them. The staff in the special care units introduced themselves by name to the families, and identified themselves as the one who would be taking care of the patient.

Four patients had post operative psychoses, with hallucinations, two had confusional episodes, and five had episodes of atrial fibrillation. There were no other major operative or post operative complications. The effects of "set backs," such as paralytic ileus, have been described. A postponed discharge while the patient's heart was monitored while being withdrawn from quinidine, like the ileus, was more disturbing to the patient than the family. The family was more concerned with the patient's safety and that they would be in "good hands" than keeping a discharge date. For example, the husband of the patient with the ileus said to his wife: "You stay here, I don't want you home with problems."

Relational work. Relational work during the phase of confrontation (hospitalization) included the work to maintain and manage family relationships in the face of changing demands, identities and situations as well as the need to make and maintain effective new relationships with care providers.

In managing the existing family relationships, the family had to coordinate and delegate tasks and roles in the absence of one of its members and to manage the added work of visiting the patient. The

patient often played an active role in the orchestration of family participation.

Even in the families with multiple members, where many could be called upon to share the work, one central "care partner" was designated in the family, or emerged by the time of hospitalization. The others were given peripheral or part time roles. This designated care partner was not always a true partner, but was the one who took or was given the ultimate responsibility to "carry the ball".

Adult children of spousal care partners played peripheral roles. They were not brought into the crisis except to be kept informed, and to visit the patient occasionally. How the "care partner" became designated as such had primarily to do with residence (who lived with the patient), as well as relationship and closeness. Spouses were the care partners in all the spousal families. Two adult sons alternated until the mother went home, and then the son who resided with her took the role exclusively. Friends and neighbors did not figure prominently in the support networks of the study families during hospitalization, with the exception of the Black families, who had lots of people coming and going throughout.

The (precipitous) discharge of one patient illustrates the primary care partner designation and how it worked. The patient's sister was at the family vacation home hosting a family reunion when the patient was informed that she would be discharged the next day, six days postoperatively. (All had counted on a ten-day hospitalization.) The patient said:

I called my niece last night. She said she'd bring me home, then she couldn't, she had an appointment to take her daughter to see the school psychologist. She called K. (the sister), and they said they'd leave earlier than planned, be here about

noon, later if I know them. They arrived at about 11:00 A.M. and said, 'We got three phone calls in a half an hour last night.'

The sister had the bottom line responsibility.

Most family members related to clinicians in a very grateful and deferential manner. They regularly conveyed their appreciation and understanding of the doctor's very hectic schedules. They often remarked to the researcher how busy the doctors were, and how young many seemed for the responsibility and work that they had. Only one patient and his wife and the wife of another patient expressed disappointment, or anger at what was perceived as the "short shrift" of the doctor's attention.

Observed interactions between the surgeon and the patient or the family were intense. The patient or family member listened carefully, and seemed to follow the surgeon's lead as to tone. The surgeons, perhaps sensing the nervousness of the patient or the family, often made jokes, or tried to present their findings in a light manner. After one surgery the surgeon said, "While we were at it, we even fixed his hernia!" (laughter all around).

After an initial awkward exchange because the surgeon mispronounced his name, the patient and surgeon joked about the surgeon's upcoming trip: "Don't work the whole time, have some fun." Surgeon: "I'll do my best to follow that advice." (laughter all around). This patient's open dissatisfaction with the intern just before his discharge has been described. He did not bring that up in his interaction with the surgeon. One husband of a severe diabetic patient said: "The doctor, he said she'd be up and jogging after this surgery. We don't need that, just to be pain free, that's all we want."

There was a pervasive lack of assertiveness on the part of families to initiate contact with care providers, to ask questions throughout the hospitalization. One situation is illustrative. The patient complained of severe pain in her great toe, beginning the second day after surgery. The daughter said: "I want to talk to the doctor about her bruises, some scrapes and the left toe is bruised." [How did you come to notice these?] "I checked her out". Four days later, asked what her main concerns were at this point, the daughter replied,

The toe. Everybody just looks at it, don't say nothing. In the CPU the intern said he wasn't sure, could be several things, like debris. [Did he say what the debris was?] When they clean out the artery, some pieces break off.

This was a correct explanation, but the family wanted a definitive statement from the surgeon:

I left a note for him to call me, they put it in the chart. He hasn't called me yet. [What do you plan to do about that?] Call him. [Do you have his number?] No, I can look it up in the phone book.

She never called him. A note in the chart said "probable small emboli L great toe and second. Should resolve spontaneously although painful." The next time the toe was discussed with the surgeon was on an office visit after discharge. The toe was still very painful and discolored. (He apologized for forgetting to call back after getting her note in the hospital.)

Another patient described the doctors as "beautiful, just beautiful," but in the same interview complained that she had not been told how serious the operation was, or what she would have to go through. "If I would have known, I wouldn't have gone through with the surgery." In an extreme example, a patient's wife complained to the

researcher that a doctor examining her husband had stepped on her foot without apologizing. She didn't say anything to him at the time.

The family's facility to make relationships with staff was generally related to higher socioeconomic status and veteranship. In one case, however, "veteranship" had the effect of making the patient and his wife more wary and defensive.

As in the accommodation phase, knowledge work was again closely tied to family relationships. Evidence of active work to understand "what is happening here" in the sense of open, direct family discussion, was observed in a small minority of families' interactions, those with the more open partnerships, who seemed to work as teams. These "partners" took advantage of opportunities to learn and created others. For instance, in one of these families the wife asked the investigator, in the patient's presence, "What causes this, anyway? Why did he get this? What's going to happen?" On other occasions, they both discussed their need for more direct communication with the physician, the betrayals in the past when they were not told the "whole truth." On the day of discharge, a few minutes before leaving, the researcher remarked to this wife, "Well, it's over, you're going home today." She responded, "No it's not. I'm most concerned about will this happen again, and what can you do to prevent this from happening again, anything?"

Another example of teamwork is that of the patient who asked the doctors to wait for his wife to explain the surgery and the problem. She looked back on this session, engineered by the patient, as extremely important to their ability to cope with the hospitalization:

"I don't know what I would have done if I had missed that meeting on the first day. It might have been just a lucky

accident that I was here, but it sure helped. I'm the kind of person who likes to know, good or bad, so I can cope with it, R. too.

On the morning of discharge the son of another patient brought up his concerns, such as how long his father should stay with them for recovery, what to do in case of emergency. He did this as spokesman for his father, who actively participated in the discussion.

In contrast were the families who did not openly discuss the illness or the recovery with one another. They had concerns and questions. They discussed their concerns with the investigator but not with one another. They described coping philosophies that matched their behavior: "Not to do too much, not to talk about it too much. We don't talk, examine things, describe things . . ." and, "He doesn't complain or talk about his health. I have to guess."

The family care partner in the "non-partnerships" was caught between their need to know and the need to preserve and maintain their relationship with the patient, to avoid conflict. When asked why she did not speak to the doctor about her concerns and questions (brought up in research interviews) the wife of a patient replied, "Oh, no. I wouldn't do that. I can't talk in front of A., he doesn't want to know, or hear about it at all." On suggestion that she call or speak to the surgeon on her own: "Oh no, I don't want to know. It doesn't make any difference, really. I just want them to do their best for him. I'm not a doctor. I'm not one that needs to know all the details."

Other, more mid-range families (in terms of partnership versus isolated) approached and retreated from information and the illness as topic of family discussion, but were generally held in check by the absence of an invitation or the spontaneous offering of information.

The "turning over" of the patient and his care and abdication of the "need to know" to the authorities was more evident in Black and Hispanic families who held the doctors and nurses in a kind of unquestioned esteem and authority. One Hispanic husband expressed his thrill and surprise during the home visit interview that the surgeon drew a picture of the operative procedure for him after the surgery:

You know what was so great, so wonderful, the doctor took time to talk to me afterwards, to explain what he did. I never heard of that. In my country, the doctor, he is God, but here, he is a person. To be concerned about me, that is really something. When he drew that figure, it was great. In my country, you say, 'You do the surgery, you do your job, and I'll do mine, I'll pay you.'

In one of the Black American families the husband said: "I said: 'Doctor, you do your job and I'll do mine. I'll pray'."

Home work. Home work figured prominently in the family's adjustment as the family coped with the disruption of hospitalization to family life routines. The family had to schedule their visiting, juggle time schedules and work schedules. The one family with small children in the sample were by far the most stressed by the practical demands imposed on them by the father's hospitalization. They also lived out of town, about an hour's drive from the hospital, and both the patient's son and his wife worked. They visited him only twice in the ten days of his hospitalization, but talked and visited on the telephone frequently. The son had to get his father's car out of the hospital parking garage, since his father was admitted directly from the angiogram to the hospital. He drove in after work to discover that the garage was already closed and would be over the weekend. They had an expensive garage bill to pay by the time the son could get back to pick up the car.

Families with more members seemed to manage the additional burdens of routine home tasks and the hospitalization with less stress, although adult children of ill parents were not asked to and generally not expected to assist in any practical sense. The wife of one patient, 70 years old, continued to babysit her granddaughter while her daughter worked throughout her husband's hospitalization and recuperation.

Resources other than family were sometimes mentioned but did not figure prominently in any of the families discussions in the interviews. Ethnic differences in patterns of family involvement were evident. The Black American families had multiple family members and all were involved to some extent. The Hispanic family called upon their children and their families, but not friends or neighbors. (The patient's husband stated: "Our family is our friend.") Access to the patient by other than immediate family was in fact strategically limited by five study families of European heritage.

Working family members juggled work schedules to fit with visiting the patient. No one took significant time off from work to manage the hospitalization. They took a few hours in the morning, or an afternoon off, but no one took whole days off. They said they were reserving time off from work for the early recovery after discharge.

Non-working family members took on most of the visiting and "staying with the patient" work. The son in one of the Black families, who had been in the special care unit all day with his mother was asked if the family members were taking turns staying there. He said: "No, we are not taking turns. But since I am on disability and not working now, this was something that I could do to help my Pop."

Hospitalization was a kind of occasion that the family rose to meet. As one wife described it: "When I'm in a crisis, it totally dominates me. I just want to be there all the time, in case I can do something." The granddaughter of one patient in the Cardiac Care Unit, was asked how she felt about being the one elected to stay with the patient: "I like it. I enjoy coming. It gets me up and moving for the day. I lost my job and this is my job now."

In the Hispanic family, the father was relieved in his duties as owner and manager of a liquor store by his sons so that he could get up to the hospital to see his wife. "They say this is my moral obligation, I gotta be here, so they take the store and I come."

Families who travelled to the hospital from long distances had to close their houses, and take residence near the hospital. There seemed to be a sense of loss and discomfort for those away from home without activities that made up the substance of their daily lives.

Generally, families with closer emotional ties came more often and stayed longer hours. The patient sometimes regulated or limited the visiting for the family in the more reciprocal relationships, as did work schedules and other competing demands on the family's time.

Visiting became more burdensome as hospitalizations became longer. It became a burden, they came less often, the patient complained: "It gets pretty lonely, and the days are so long sometimes." Another family member said:

I'm skipping some days now, I feel bad. It's been real difficult going back and forth, just me and K. My brother has been sort of trifling about this. K. and I have carried the ball. She gets kinda sensitive when we don't come. It's natural.

Travel to the hospital for visiting was a major event for some. One family brought their motor home to a local RV park, and stayed there. Visiting took the whole day for those who had distances to travel: "It cuts into the whole day, there isn't even time to go grocery shopping when I get home." Negotiating the streets of the city and parking made one wife feel "like a country girl," who said she did not realize until this event the extent of her dependency on her husband.

Health work. The families' health work during hospitalization was examined in relation to activities directly involved with insuring the safety or physical well being and recovery of the patient. Health work depended to a great extent on knowledge work. If the family was not accurately informed, they could not make accurate assessments or take action.

Even without special knowledge, however, family members did health work activities that did not need special technical information, such as walking with the patient, or "translating" for the patient:

She was desperately trying to tell us something, tell us that something was wrong (the patient was intubated). [What did you do?] It was all under the covers, something was not right under the covers. I wondered is she dirty? When are they going to bathe her? She wasn't wet, but she had sticky surface on her skin on her legs. It think it itched. I worry when I'm not here. They might not pay attention to what she is saying and she will freak out.

Knowledge from past experiences was brought to the present for interpreting events, signs and symptoms:

When I saw her face all swollen,, I asked about it. They said it was fluid. I had to leave the room. My brother looked like that right before he died. [Tell me about that, when your brother died.] He died of a stoke. He was 41. He died four years ago, he was all swollen in his face. He died in the hospital.

A patient's wife said: "The doctor said he'd be in here (CPU) two days. I didn't know about that, kinda shocked. Like my mother, she was in four hours. You could peek into the room, that's all."

The "carry over" wasn't always acknowledged. When asked "do you think the experience with your mother influences how you think and feel in this situation with your husband, she said:

No. But I shoulda called the 911 for her. I called her doctor, he said she just needed some rest. The nurses didn't get her up. She needed to walk and then they sent her home to die. She died the day she got home.

A few family members sought out information to interpret the meaning and seriousness of signs and symptoms, but most did not. Veteranship and education seemed to positively influence this behavior. The wife of one patient who had a kidney transplant ten years before this surgery said:

He's holding fluid, almost 20 pounds. Look at his face and his hands." [Have you said anything, or have you been told what this means?] I asked the nurse what it was. I went to the desk, and said he's swollen all over. She said it was the prednisone and the IV. They are protecting the kidney with the larger dose of the prednisone.

One husband (an engineer) reported on the home visit that he was quite concerned when his wife told him there was an irregularity with her heart beat. [What did you do?] "That's something serious, when you hear that. I walked right out and asked the doctor. It was atrial fibrillation."

For most families, there was remarkably little participation in care in the hospital. This was largely a function of not knowing or not being sure of what to do. Families were not given guidelines for health work, or included in care by the health care professionals. When asked, except for a couple of family members, most had not seen the surgical

incision, even when given the opportunity. (Many had their first view at home after discharge.) In one case, the patient's wife described her role uncertainty and response to a clinical situation in her husband's care. She said that her husband had become hysterical when a nurse raised the head of his bed:

The nurse had him sitting up in bed. She moved him into that angle, he was uncomfortable, not supposed to be at a sharp angle. [So, what happened, what did you do?] I didn't do anything. A. started yelling at her to stop, he said stop putting me up and down. [And then?] She stopped, and walked out. [And then?] And then I left. I understood that he wasn't supposed to be sitting up for at least five days. [How did you learn this?] The doctor told A. He said he could not be bent and he was bent. [What was the eventual outcome?] A. put himself down. He was all upset. He wants the hand gear thing next to him now, and he was mad at me that I didn't put it up on the bar.

Another patient's wife said: "The doctor didn't tell me nothin'. Remember I said my sister-in-law said for me to grab his arm? I wouldn't do that, but he never told me nothin'." The patient said: "I didn't tell him to explain anything to you. I didn't want you to worry. I didn't tell you about this heart thing." "Then who told me, I knew about it." "I told you, later, after I found out that it wasn't a blood clot." "Oh."

In contrast, three families in a pilot study for this study were much more involved in the patient's care, dispensing medications, making beds, feeding the patient, sleeping over in the room, etc. The patients in the pilot were heart surgery patients, however, and received more systematic attention, were involved more by the staff, and were more worried.

There were no self-reported or observed instances of the family's actively becoming informed (initiating discussion) to be able to do health work after discharge. Nor did families complain about not

receiving specific discharge instruction. Questions, concerns about care and a desire for more instruction came retrospectively. A patient said:

Could'a used a lot more information about the hurting, the exercise, not to overdo it, diet, stomach aches. I'm doin' this for the first time in my whole life. I checked with the doctor, he says all this is normal. I wish I'da known that, it'a saved me some worry. Boy, did I overdo it.

One wife described her experience:

I had loads of questions and none of them was answered. My timing was such that we may have passed in the night. [Any instructions about discharge care, what to expect?] One nurse who was on duty when we were leaving said to feel for pulses once a day. It made me real nervous, more stress of responsibility. I couldn't find the pulse. She said to watch if the feet got cold. I don't know how much he can get around, and he has a little blood on the incision.

This wife had asked the researcher on the day of the surgery what arrangements for taking time off from her work would be necessary, would she need more time off when her husband came home, or time off now? What kind of care would be necessary, what should she expect? Her early questions remained unanswered at discharge.

One patient, whose discharge had been delayed for cardiac monitoring, had done some anticipatory work on his own in preparation for discharge. He told the researcher that he wanted to go for a long walk and climb some stairs before going home, while he was "all wired up," in case there was a problem, he would know about it before he went home. (He lived in a third floor Victorian walk-up.) The researcher checked with the nurse assigned to the patient, and she said that she "guessed he could do that". All three: the patient, the wife and the researcher left for the walk and the stairs. He led the way. His wife told him to slow down, and to hold the railing. He said to stop henpecking him, and did neither.

Risk management was routinely discussed in one site during the discharge meeting with the nurse. It was also, by report of one of the clinical nurse specialists at that site, a topic which was discussed throughout the hospitalization, but not in a formal or structured way. The families from this site seemed more acknowledging of their disease and did display knowledge of risk factors. In another instance previously described, a surgeon took the opportunity of his meeting with the wife after the the surgery to discuss the importance of risk factor management.

Psychological work. Psychological work for families in the hospital was focused on "keeping their cool," "configuring," so as not to disturb, preserving their sense of competency and trying to get along, not cause trouble, and to help the patient to do the same. Asked about what she might have learned from her experiences in the hospital, one wife remarked that she learned how to hold her anxiety down and keep in control.

The wife who left when her husband was upset; another who felt the need to explain that her husband "can be a problem patient, since he is used to getting his own way", when he became angry with a nurse who withheld his pain medication; the husband who said he didn't want his wife to worry; the son who complained that the doctor should have called him; the husband who wanted to call when the surgery went three hours past the time he was expecting her, but didn't; the families' remarks about how hard it is to ask, and that they wished that they would not have to; all these were part of the psychological work of identity management and performance control.

The family practiced restraint and self-control in the service of the patient and his care, in the service of their own sense of competency and to maintain a positive identity in a strange and highly charged emotional environment where rules for behavior are implicit rather than explicit and where the family's role was uncertain. As families encountered the acute distress of the day of surgery they had to work to manage their distress without assistance. The husband's tracking himself at "at least eight miles" of pacing on that afternoon, and his remark, "they told me not to worry, so of course, I didn't," is illustrative.

One family task during hospitalization was to comfort the patient, a combination of health and psychological work. Comforting was mainly accomplished by attendance--visiting and being with the patient, sometimes for long hours, even while the patient slept. Some families saw the visiting as their duty, and thus, their role and task, and seemed to derive a great deal of satisfaction from it. Families were rarely observed touching, rearranging tubes, bathing, or repositioning the patient (physical comfort measures), although they helped the patient in and out of bed, and walked with them. There was more touching in the intensive care units, perhaps because the patient was less verbally communicative.

Emotional care or emotional support was indirect. Families were not observed talking about their feelings or distress with one another. In the more mutual relationships, family could share their distress with the patient, in others, they did not or could not.

During hospitalization, family members had to construct their role in an uncertain situation. Most chose to "play it cool," "to handle

things one day at a time, as things arose," rather than devise a "game plan" or a conscious strategy method for managing. Several families did plan and control such things as who could visit, and when: "We asked for no visitors until I get back to (the regular care unit)." Another couple said:

We worked as a team, generally, we took it one step at a time. We both understand that we want no visitors, and no flowers. I said to send money! We learned from past experience that when somebody's sick it's not the time to visit.

Patient and family control of the domains open to them had varying results. The mother who restricted her sons' visits until four days after surgery had a post operative psychosis. The staff called the sons to come to the hospital. One of them remarked: "She got pretty lonely in there."

One wife complained of boredom after the first few days. She apologized: "I hate to think of this as a little vacation, but at least I can go shopping. If I didn't have that, I'd do something else. After my sons left, I planned my day and I was fine."

Some patients helped their spouses to manage their role in the hospital, asking them to bring things in for them, like hobbies or the household bills to sign, told them not to come in, and when they were there, when to leave. The mothers did this too much, perhaps to their own detriment. The more relaxed "partnership" couples were observed in "parallel" activity: together, but doing separate things. Other family members made short visits, and used the telephone to visit and keep in touch.

Containment and Integration During Hospitalization

The concept of containment seemed to explain the families' behaviors and interactions during hospitalization, but under a new and different set of conditions. The strategy worked, as it did during the first phase, to manage the family relationships and in this phase the family' relations with staff, in order to minimize disruption and distress. During hospitalization, the distress mounted in intensity and in its variety of sources. The disruption was real and could not be staved off.

Conditions influencing the employment of strategies of containment during hospitalization are several. For most of the patients and families the hospital was a completely foreign environment. The hospital and the providers were patient and care system centered.

The clinician's knowledge is highly specialized and there were many unwritten rules, known only to those inside the system. The care providers were clearly in charge, had total authority in the situation. The family's access to the patient was unclear and under the complete jurisdiction of the care providers.

The family was essentially left out of most of the day-to-day planning, even if they were kept informed of the patient's condition and the general plan of care. Schedules changed without notice. Families had to "scramble" (a family member's word) to keep up with and comprehend the pace of events.

One husband, working the night shift, was called at 5:30 A.M. by his wife to tell him that she would be going to the operating room at 6:00, one hour earlier than they expected. He told his boss he had to leave and hurried to the hospital. He got lost on the way, and parked

his car down the hill from the hospital. He walked so fast up the hill, he said, that he was out of breath and had to stop a few times. He arrived on the unit to find that he was too late, she was gone. A nurse saw him and said to go down to the fourth floor and showed him the elevator. He did, and asked where to find his wife. He found her in the hallway outside the operating room. They both got to see the surgeon, who said he expected things to go well, and that the surgery would last about three hours. He was able to talk with his wife, give her a kiss and to tell her to stay strong. He thought it was a miracle that he did catch up with his wife that morning.

The relative exclusion of families in care planning and lack of provider-family interaction was most likely a combination of an approach-avoidance conflict, a combination of many factors, on the part of the family. Also, there appeared to be an absence of an explicit invitation or opportunity presented by the providers to explore their thoughts and concerns to learn about the disease and to do the knowledge work for integration with some assistance. For instance, the 28 year old son of a patient who underwent an aorto-femoral bypass graft spoke to the researcher five days post operatively:

I'm very concerned, there's something I'm not happy about. I didn't get to talk to the doctor about the results of the surgery. Is it 50-50 or what with the circulation in the legs? And when she comes home, what about that? It's so much that she has been through. Will she really be better?

His remarks demonstrate an effort to acknowledge and to integrate the significance and meaning of the surgery. He did not call the doctor himself, however, nor did he talk with his mother about these concerns.

This young man's further remarks illustrate another condition of containment: the operating assumptions, or rules, of the situation as they were interpreted by the family.

He was supposed to call me, to tell me that the surgery was over. He called me at work, but I had left. I left my home number on the chart, too, he should have called me. [Did you try to get a hold of him?] No, he should call me.

Another patient's husband said: "My son wanted me to call when we were waiting. You want to and you don't want to; you don't want to disturb, you know?" The family's hesitation to ask, coupled with their their sense of the rules and expectations of the situation was observed repeatedly in the study.

The family and the patient operated at different levels of awareness and integration at different times. For those families with more open communication there were different consequences; more unison, more developing awareness, problem solving, more acknowledgement and a sense of work to be done, a team approach. For those with less open communication, there was more isolation and conflict.

Most of the patients and the families were not prepared for the distress, pain and general misery of the surgery and early recovery period in the hospital. There was a kind of post hoc assessment, as the family and the patient lived through the surgery and hospitalization and and confronted their seriousness. "It's been rough, real rough. If I had to do it over, I wouldn't. If I had known, I wouldn't have gone through with this." This varied with the type of surgery to some extent. The femoral popliteal bypass patients more easily maintained a "localized" definition. One of these patients complained about his night in the special care unit: "That's for sick people, not me."

The eventual integration of the fact that they were dealing with a serious disease depended on many factors, however, and these overrode the initial "localization" in their definition of the situation. For instance, one patient who underwent femoral popliteal bypass graft had a

concurrent diagnosis of an abdominal aortic aneurysm that would have to be monitored. That plus a supportive and open, moderately "confrontive" family encouraged his acknowledgement and thinking.

How families responded to the patient's hallucinatory episodes provides an illustration of contained concern. In one case, the patient was quite adamant and upset about the fact that no one believed her when she told them that she had witnessed a shooting in the intensive care unit. Her sons were called to come to the hospital in an effort to calm her. The sons never asked the staff, never approached the staff to discuss the problem. One remarked in a later study interview that he thought it was not handled well: "I received a call from someone in P.R. about my mother's hallucinations. The doctor would have been better. I suggested the doctor, but he didn't talk to her or to me." At the time, during the hospitalization, however, he did not assert his wish to talk with the doctor.

Another patient's wife left the room when the patient and the interviewer discussed his hallucinations experienced while he was in the intensive care unit. She said later that she thought he wanted to speak privately about the experience. The wife of another patient said she expected that kind of reaction to all the drugs her husband was receiving so did not discuss it with anyone.

Summary

During hospitalization, the major task or challenge for the family was confronting the seriousness of the illness. The family was forced to cope with multiple stresses and distress in the form of uncertainty and fear associated with the surgery itself, observe the pain and

discomfort of post operative recovery, and experience the actual disruption to the family system brought about by the hospitalization of one of its members. As one patient's husband said: "She looks a lot better now. You should have seen her before. I had no idea what was involved."

The families who were more active and involved before hospitalization tended to be the families who were more active and involved during the hospitalization. These families were those who had been on "aneurysm watch," or who had established family patterns of open communication and partnership in problem solving.

One site was somewhat more acknowledging of family needs and concerns than the other two, and the families and patients were to some extent more exploratory, more openly acknowledging of the disease process which brought them to this surgical event. Even there, on the day of discharge, a patient asked:

I want to know how I can prevent another one (aneurysm) from developing. How can I find out more about my circulatory system risk? [Have you spoken with the doctor, you have asked this before?] No, I forgot, and he was in a rush.

It is possible to see in this example the work of integration beginning, but also the hesitancy and the practical difficulties of articulating concerns to busy clinicians in the hospital.

Family members constructed their roles and the meaning of events based on their own "configurings," and in the context of their relationship with the patient. For some, the distress encountered during hospitalization came as a shock and betrayal; for others, it was taken in stride, "contained" by a strategy of taking things one day and one event at a time, not delving into the discrepancies between their

expectations and the distressing realities of the situation, not making demands, watching and waiting.

Interactions with care givers were characterized by a general lack of assertiveness or directly expressed complaints. It is as if the family needed to carefully discriminate and decide when or whether to act, to intervene, when it was worth the risk of causing trouble. There was a pervasive hesitation about complaining or asking questions.

There was no systematic inclusion of families in the hospital. Families were extremely grateful for any consideration of their needs, and generally expected little if anything from the staff for themselves. They were not assigned care functions or tasks, were not invited to participate in care, or instructed about the patient's recovery needs and care during hospitalization. Nor did the families express a desire or a need to participate in care, other than an occasional question or clarification of a procedure or professional assessment, such as temperature or blood pressure.

In general, the families maintained a pattern of opportunistic and "piecemeal" information gathering throughout the hospitalization and, except in the case of a discharge meeting scheduled as regular part of the care at one site, the family remained as an unassertive, worried, poorly informed bystander by discharge. They "contained the crisis", even at its peak, by working to control their own behavior and emotions, trying to interpret situational cues for their proper role and performance and to understand the meaning of events and changes in the patient's condition.

Developing Awareness and Acknowledgement: The Recovery Phase

During recovery, the family achieved an accommodative integration of the surgical event and accumulated experiences in the family's life. For each family, the events of surgery were integrated in a unique manner by three months after discharge, but variation in conditions over time and families' situations seemed to influence the various outcomes for families.

First 72 Hours after Discharge

Emotional lability. For many families the first days at home were an emotional time. For many, it was a time of euphoria, high morale, and relief to be home: "It's lovely," "I feel lifted up." In some households, there was a festive atmosphere: "She's bustling around, her son and grandson are here, lots of people, lots going on, it's busy and festive." "My family is all here, everybody is doing for me, I had some good homemade soup." Others described the pleasure of taking a shower at home, getting to their paperwork. Others were a little less sanguine: "So far, so good," "I'm still alive." "It will take time, each day is better than the last." The high feelings were often mixed with depression: emotional lability. This was unexpected and a source of concern as indicated by these comments: "I cried on the way home, I don't even know why," "We're optimistic people, but I wouldn't say my morale is great right now," and "I'm crying a lot, feeling sorry for myself, I don't know why. Physically, I don't feel so bad."

Irritability and anger on the part of the patient was also a part of the first 72 hours for some families: "He is so crabby, so

insulting. He blew up at me when I told him not to cross his legs," "He's on edge, called me a name already. He sneaked out this morning, walked nine blocks. I'm hidin' his cigarettes."

Family responses to depression were guarded:

[How's R.?] He's very energetic. If he has any feelings he don't show any sign, no sign of feeling sorry for me, not to baby me, like he knows, if he does I'll open up and I'll cry. A lot of times he just say are you OK? I just touch him to let him know I'm OK. I'm not used to being so dependent.

Variation in responses. In general, the older patients and the diabetic chronically ill tended toward a "convalescent" response, staying in bed, and in bedclothes. The younger patients, even including those with histories of severe heart disease and coronary bypass surgery, "pushed" themselves, starting the day after discharge. One woman, a hairdresser, whose aorto femoral bypass was followed by a carotid endarterectomy and preceded, three years before, by coronary bypass surgery went back to work the second day home for her "sanity." She said that she had to be with people. Her husband called her ten times the first day.

Another of the younger patients, after an aorto-femoral bypass, who had done the laundry, gone grocery shopping, done the bills in the first two days after discharge, said: "I believe a person should get up and get working. I know that Judy [research associate] was surprised, but 45 is young, and I was up and able in no time." Her morale suffered, however. She admitted, regretfully, that she overdid it, was tired, sore and feeling low about it.

Another patient proudly announced that he was out at dawn the day after discharge and had walked nine blocks. His wife said "He sneaked out this morning." He, too, regretted his outing.

Patterns of family activity. Patterns of family activity during the first 72 hours were focused on supporting the physical needs of the patient: assistance with getting in and out of bed, meal preparation, and "watching over" the patient. With one exception, a husband who took a week off from his work, the working family members all continued to work, making arrangements for other, non-working family to watch the patient, or leaving the patient alone at home. One husband said:

Everybody work hard. [What if Mrs. C. would need someone at home?] If she need somebody when she gets home, B. (a daughter-in-law) gotta come. She's the only one not working. [B. has two small children.] She can bring the children.

The youngest (45-year-old) patient in the study who resumed all of her normal household activity the first day home explained that did not expect help from her husband, since he was busy running two businesses. He offered to hire someone to stay with his wife, or to send over his receptionist. She refused to allow him to hire anyone, stating that she "wanted to keep the household as normal as possible."

Adult children were not involved in the early recovery except in one case, where the son and daughter-in-law and their five-month-old twins were residing with the parents. The working spouse said: "My daughter-in-law is there, and nothing terrible is going to happen."

Before discharge, a wife (with two adult daughters who lived nearby) had said:

One thing I am wondering about, what if I go out at night, I wonder what I'm going to do? I don't know anyone around I could ask to stay with him, I wouldn't be comfortable. Perhaps my housekeeper.

Asked much later during the recovery, when she was describing how constricted her life had become because she simply could not leave the house, about the possibility of the daughters as a source of assistance,

this wife said: "Oh, no. They have their own families, responsibilities, their own lives. I wouldn't ask them."

The circumstances of the patient's discharge were reviewed by several families on the 72-hour call. One wife described:

Friday night one of the doctors said, 'Are you ready to get out of here?' So, he said 'sure.' The doctor said, 'At some point, you can get rest at home too. Rest at home can be as helpful as rest here.' The vascular book says 10-15 days. That was my timetable. It needs to be revised. It also says you shouldn't sit erect, which concerned me. He was doing that there, and now.

Major reported morbidities in the first 72 hours were pain and fatigue. These were, in general, expected and were not considered as problems. As one son said:

She's in some pain, has Motrin. Not sure it works, not enough. [If you think she needs more what would you do?] I imagine I would call the doctor, if I needed to, but, no, there are no real problems, everything's fine.

For some, the amount of fatigue was unexpected, and contributed to depression. One patient said: "I can't even comb my hair, I try to do things and I can't." Another said: "I'm resting, I feel knocked out."

Family work. The interaction between knowledge work and relational work was evident in this early recovery period. Patients and families had to figure out the details, fend for themselves and make constant judgments during this early recovery period. Families were without authority, since they had not been included in instruction, which created conflict in some cases when the family tried to intervene in the early recovery.

As before hospitalization, the family's behavior in relation to recovery management was moderated by the relationship with the patient, although the family was more assertive at home. The patient's negative response to their attempts to monitor or intervene in recovery was often

correctly anticipated, but most made an attempt to do so in any case, braving the consequences.

The uncertainty and room for individual interpretation of these instructions created a focus for family conflict when the family tried to participate or monitor the patient's activity. Where there was no open conflict, there was contained conflict: watching and worrying. Another patient's wife expressed the difficulty of managing without information. She said:

I don't know how much he can get around. The doctor said 'ambulate and activity as tolerated.' He has some blood on the incision. He says it's nothing and he doesn't want to do anything about it. He minimizes everything, so if the doctor said anything else, I don't know. What should he be doing? He is strong willed, and I don't know. Maybe they could have something in the system, for instance, with my mother a social worker says you can expect this and this. It could have been a nurse. You can say probably, or could be, or, the earliest time could be, but it differs. It doesn't have to be a doctor, it could be a nurse.

With two exceptions, there was no interaction with care providers during this early period. One surgeon called to check on the patient's progress and to set up an office visit appointment during the first 72 hours, and one family called the surgeon. The call to the surgeon was due to the patient and family's alarm about a "very swollen foot" that began on the day of discharge and worsened over the next twenty-four hours. The patient went to bed to alleviate the swelling, and it improved somewhat, but returned when he got up. The wife was indirect in expressing her pique at the situation:

He said to lie down, no sitting, no sitting with the leg elevated. Lie down or walk around. It's better now. You know, it was swollen by the time we got home. It was two hours before we could leave, and they kept him in a chair the whole time he was waiting for the ultrasound, that probably made him swell, that and the long ride home.

There seemed to be a "why didn't they tell us, or prevent this" message in her voice, but it remained unspoken. (Before discharge she had said to the interviewer: "They said to stay off the leg, don't stand on it too long, elevate it. He'll know it if he does, I did after my foot surgery.")

In general, however, this early period was not reported as a time of great stress or major problems. Most families took it in their stride and managed more or less effectively, coming to the uncertainties, guessing correctly or simply living through these and moving on, accommodating the role changes, and juggling work schedules. The families rallied, and like the early days of the hospitalization, they rose to the occasion, and worked hard to take care of the patient. Later, in retrospect, families and patients had regrets that they had not been warned enough, given more instruction or more support.

Health work continued to be moderated by incomplete knowledge work and family relationships at 72 hours. Although health professionals were available for consultation about any problems that should arise, the family and the patient were left to define the problems; to decide what problem merited or required a phone call to the physician, and what could wait until the scheduled visit.

There were two alarming complications within the first 72 hours: one wound dehissence and one case of severe swelling of the lower leg. The patient and family took appropriate action in both instances, i.e., called the physician. Both complications were costly in terms of family and patient distress and uncertainty, however.

Knowledge of major potential problems such as graft failure or graft infection, what to observe for, etc., was not directly assessed in

the interviews, but there was no mention of these. Had they been informed? Did they think about graft failure? Had they asked about it? (In a later interview, at one month after discharge, one patient said that he asked his surgeon how he would know whether the graft had come apart.)

Containment

Containment played a role in this early recovery period in the carry over of family's general lack of preparation for the patient's homecoming and the patient's and family's "wait and see" posture, rather than asking questions, or actively preparing themselves for discharge. With few exceptions, what they didn't know, they didn't ask about. One patient said: "What I don't know won't hurt me. I let the doctors take care of me. They went to school." The refusal, or lack of activity to obtain outside help during this time was another form of containment.

Some families anticipated and were "on guard" for the patient's behavior in the role of the convalescing patient: "Maybe when she gets home she'll be more demanding, she'll object to our encouragement." This "guarding" on the part of the family fit conceptually with containment as the family worked to keep the patient's demands or role and behavior change in check. This guarding had consequences for the management of recovery problems. On the home visit to this family, the patient showed the researcher her incision, which was quite reddened and had a small opened area. When asked if the family had seen it, the sister replied, "Yes, but I didn't say anything, I didn't want her to get all worried." The brother-in-law said, "Don't make a fuss, she'll worry now."

Some couples had had experience with role changes to accommodate a convalescence, which they drew on; some did not. As one wife said of her husband, "He's domesticated." He said, "I'm busy, but I've taken care of her so many times." Those with more experience had less difficulty.

Husbands had more to say about the work of caring for their wives than did wives who cared for husbands. One husband said: "I'm bearing up under the nursing strain. I kind of like keeping house. I get all my ducks lined up and it's no big deal. I'll be glad to get back to work, though."

Balancing the demands of the patient with other, competing demands was a "headache" for a daughter with her own family:

She doesn't want to stay here. That means we gotta go over and spend the night, throws things off the rocker. I got angry last night. I asked C. (one of her daughters, 14-years-old) to stay. She came home, said 'Big momma doesn't want me to stay.' I called her to ask what was going on, why not have C. stay with you? She said, 'I'm 65. I didn't like the way C. was talking to me, I don't need anybody to tell me what to do.' I said 'OK, I'll come over, but later, and I'd rather not spend the night. My other one, 11, has the flu.' Things are rough around the edges.

In another family, the patient, a father, was easier to get along with:

He's sort of pushing it, I think, but he minds me. I send him off to bed with my son, they nap at the same time. It's just been three days, and weekend days. Ask me next week. It's been great so far.

As the recovery progressed, the early confrontation and limit setting in the first family was helpful in coping with the patient's demands, although it was stressful. The mother did not "contain" her demands, and the daughter did not "contain" her irritation. They

compromised. (By three months after discharge, they said they felt closer, more open and more honest in their relationship).

In the second family the patient made a conscious effort to fit the family; to not be a burden, to be helpful in ways that he could be, like baby-sitting his three-year-old grandson and taking the family out to dinner a couple of times. This family, too, was pretty open and "uncontained" in their responses. The patient worked at fitting in and reciprocating. The daughter-in-law said:

Actually, he was very helpful. He took care of N. (the baby). R. checked in on him, but he was doing fine. R. is close to his father, and A. (the patient) was an added plus. He fit right in.

He may have done a little too much, however. The added family work of caring for him later in the week, which included a a trip to the doctor's office for a dehisance, was almost overwhelming to this young family: "It's crazy, just crazy, taking care of Dad and everything. We all went to the doctor's today. I can't even go to bed. It's wild. They should reward people for being parents. Right now I'm sorting laundry."

Conditions for the patient and family changed abruptly and dramatically at discharge. The patient leaves the ordered, highly controlled world of the hospital where he or she has been cared by people who have specialized knowledge for twenty-four hours a day, and where there was a kind of expected routine, and returns home. One patient remarked, right before his discharge: "You know, this is funny, but the regular meals, they are not even good, but it's a let down to go home. It's like a cocoon here, the meals are so regular."

As has been described, families were not prepared by their hospital experiences for an informed participatory role in recovery. There

seemed to be an assumption of rational care with minimal guidance on the part of the providers, as was evident in the almost casual approach to discharge instruction. It was almost as if it was deemed by the clinicians to be prudent not to bring up exigencies, or to delve into detail, so that the family and patient would not become alarmed, a kind of containment strategy from the perspective of the provider, perhaps. Later in the recovery, however, complications arose, for which the families and patients were unprepared. In retrospect, the families felt as though they had been abandoned and set adrift, even betrayed by not being more forewarned.

The Home Visit: Two Weeks after Discharge

Escalation of complaints. At the time of the home visit, two weeks after discharge, complaints had escalated. The patient and family were coping with new, unexpected morbidities. (For a summary of symptomatology at two weeks, by procedure, see Appendix D-1). Complaints were of continuing fatigue and pain, lack of energy, "not bouncing back," swelling of limbs and incision area, all unexpected. In many cases, the complaints were accompanied by self reassurance or minimization, in others, anger and a sense of betrayal that they did not know, or that the complication could have been prevented. For example:

We had to take A. to the doctor. His leg got so swollen that his incision opened up. [What did the doctor say?] He said it was normal. It was OK. But A. went through so many mental changes before that. It was good to hear that everything was OK. [What do you think caused the swelling?] Pushing too much, underestimating what it takes out of you. He has been depressed by this thing, when it opened up and started bleeding. It set him back. He's fine now.

The patient said:

I'm pretty good. I got a good bill of health. It's just the traumatic shock of the operation to the body. The swelling,

the blood surging through. The doctor put on a Band-Aid, said the scars have to fill in, it just takes longer there in the groin.

Another patient said:

There's more swelling than I like, and I called the office. I went in and they palpated, there was no clot. Told me to lie flat, leg above the heart. It helped, but now its back. Am I doing too much? My left knee is swollen, a burning pain down in the back, and the ankle is swollen. I will see the doctor in a few days, on the scheduled visit. I am surprised at the continuing symptoms. I made a faster recovery with the last surgery. Maybe its because I am ten years older?

Another patient:

I can't wear shoes yet, the leg and the foot are still quite swollen, top of foot still numb. They kept me sitting. What really got it swollen was the last minute ultrasound. Two hours before discharge, it started to puff up, and then two more hours in the little car. I wasn't expecting it. I noticed it before I left. He said, 'Don't just stand, walk; recline, don't sit.' They could have said that before I left.

Another patient:

We could have used more information, about the hurtin', the exercise, not to overdo it, diet, the stomach aches. I am doin' this for the first time in my whole world. I check with the doctor. He says its normal, its common, like the stitches hurting, pulling, pain in the leg. I wish I'da known that, saved me some worry, some worry for nothin.' That first day, boy, did I overdo it. (His wife's remark to this was: 'You shoulda' known.')

When the researcher arrived for one home visit, a patient and his wife said they had a "new, immediate concern, a hernia, or something, in his right inguinal area, where the incision was." It was red and hot over the weekend, and they had called their doctor, a cardiologist, who said not to panic, to take Tylenol and watch it. If it gets worse, see the surgeon. The fever was now subnormal, and the wife asked the researcher what that meant; was the body now fighting the infection? The patient said his morale was set back by the complication. He dreaded more surgery. They had been fighting. He said: "I do panic, I'm prone

to panic, and that's why I've been so nasty to J. I feel badly about that."

On a call to arrange for a home visit, the patient said that things were:

On and off. One spot on the incision didn't take, it's leaking fluid. [How much, what kind?] Quite a lot, and yellowish. I'm using a sanitary pad to soak it up, my wife's idea. [How many in an hour?] I change it about every three hours, I use two. [Is it reddened, hot, do you have fever?] No. [You need to see the doctor about it.] I have an appointment today. Somebody made a mistake sewing me up. Everything was going so smoothly and then this happened over the weekend. My wife is very concerned. We went in and Dr. S. saw us. It hasn't improved. I'm very angry. It shouldn't have been made light of.

During the home visit, he said that on his office visit the doctor had put on an Armstrong tape, because he was concerned about the skin damage from the other tape.

Such a nuisance. I can't shower or bathe. [Did he say how long it would be?] He said, 'not days, and not months either', so I figure a few weeks. It leaks a lot. I soaked through my trousers in less than an hour. [Did he say what the fluid was?] Yes, it's lymph fluid. Somebody made a mistake. They didn't sew me up correctly. He probably told the intern to close up. Dr. (the surgeon) told the intern to put the tape on tightly, to close it tightly, and he didn't, or he missed the spot. I'm more angry than you know.

Back in her own apartment after five days at her sister's house, a patient said she had developed pneumonia and was taking antibiotics. She said she "got it at her sister's; the doctor said it was too late to be from the hospital." Her sister and brother-in-law keep their house too cold, she said. "I said it was cold, they said they weren't cold." She said she wasn't sleeping well, due to her "nerves." She had a low grade fever, had shoulder pain from her arthritis, and was feeling: ". . . a little down, I'm upset that I couldn't get out of bed this morning. Maybe it's a let down, so much excitement recently, so many people, now there's nobody."

A painful and discolored great toe was still a big problem for another patient. She had been to the doctor's office. The doctor said that he was not worried, and that it would resolve itself eventually. She could not wear shoes and it hurt to walk. At the end of the home visit, she showed the researcher bedsores which she had developed in the hospital. She was treating them herself, with Maalox, and they were resolving. She said she never said anything about them because she "wanted to get out of there."

The doctors' responses to the complaints and problems were "containing." They were told not worry, "nothing to worry about," "not a big problem," or "its normal." Families did not feel encouraged to call, and were not complimented for calling with their concerns.

On another call to make a home visit appointment, the researcher asked how things were going. The patient said: "Bad." [What's bad?] "Aches and pains, tingling in the upper leg, a sharp pain through it, some angry spots and secretions on the incision. Otherwise, I'm just hangin' around, no big surprises."

She had not called the doctor about these problems, and her next appointment was in two weeks. There was no fever, she said, and the discharge was clear. On the home visit, two days later, she showed the researcher a two inch opened area, several skin thicknesses deep, on the major incision which appeared to be slightly inflamed, and hard to the touch. It was not sore. Another open and seeping area was noted on her groin incision. She asked if the researcher could find out if she needed to be seen? The researcher did call and the resident said it would be a good idea for her to be seen, and she was seen the next day.

The patient called the researcher to report that the doctor said that it was not healing from the inside. He had cleaned it out, took away the dead skin and packed the open areas. He showed her husband how to change the packing. She said she was so glad that she went, and that he was, too.

One patient with associated heart disease had been rehospitalized for chest pain after discharge. On the home visit, she was tearful and angry, and under a great deal of pressure to talk about the hallucinatory episode she experienced in the hospital, saying that no one would believe her, and that she knew it really happened. She had called her health plan's hospital to request a psychiatric consultation, at her son's suggestion. She was told there was a three month wait to see the psychiatrist.

The Family's Response

The families responded to recovery demands and complications in different ways, but there seemed to be a general trend toward controlling, or limiting the patient's demands, a careful non-reactivity or moderated reactivity, and emotional distancing, rather than a "therapeutic", exploratory response. This began earlier or later for families, but most described aspects of this kind of moderation in response to the patient's demands.

At the 72-hour call, a patient had described this control in terms of her husband's coping. On the home visit, the patient said: "He doesn't want to touch me or look at me where I had the operation. He's so careful of me, and he doesn't talk about it."

The full extent of the family's thoughts and concerns were rarely openly shared with the patient. The wife of the patient with the lymphatic drainage said:

I was so worried. I thought it was an infection. I thought to myself, you know, they cut his artery, what if it opens, then what? I said we had to get it looked at. I really pressured him.

The patient's daughter said later, at one month:

At first I was frustrated because she was so demanding. Now I've let it go. She was sort of like that before, she likes attention, likes to be waited on. I really had to watch that at first, not to cater to it. When she wants to, she can get around. She says: 'I am tired, I am weak.' It's hard to push her. My sister came out from (another state) stayed with her. It wasn't exactly what she expected. We was running around, getting ready for the wedding, having a good time. We took her shopping for a new dress for the wedding but she didn't get the attention she thought she was going to get. My sister went out a lot.

She had two areas of her incision that opened up and were infected. She had told me about it. I said 'You should call the doctor.' She didn't. It was still running and I found out and she said: 'I thought you would call.' I said: 'No, no, no.' She is still weak, just hasn't tried. If I lay around all day I get weaker too."

One patient, a mother, said that her daughter "knocked herself out at first, and then, she let me have it. She let go with all the things she had held inside her whole life, all hurtful things. If I tell you I'll cry." (Which she did). Asked how she responded to her daughter's outburst, she replied: "I was so surprised, I only said I didn't know." The researcher commented that this was a time of crisis, and that it is possible that it could turn out to be a good thing, for her daughter to have opened her heart: an opportunity, perhaps, for a more genuine or closer relationship, although it was very painful. She replied: "I can't say. She's away now, with her daughter."

This daughter had written copiously on the family assessment instruments her rationale for the very low scores, and her dissatisfaction with her relationship with her mother. This was one dramatic instance of "non-containment": the eruption of feelings, brought on by the stress of the work of recovery. The outcome, the consequences for the relationship remained to be seen.

Incomplete knowledge of health care, gathered separately and in piecemeal fashion, resulted in family conflict rather than effective risk management after discharge. Often, the patient and the family care partner knew something about the disease, and something about risk factor management, but did not work as a team.

We had an argument over peanut butter today. I said he shouldn't eat that anymore, it wasn't good for him, he just went on, and complained that the bread wasn't toasted enough. The peanut butter thing, I said it's not good for your disease. That may be cruel, but the doctor emphasized to me that he had to watch his diet to slow down the disease.

In other families the conflict was more pronounced.

Family Work at Two Weeks after Discharge

Knowledge work. On the home visit, the families engaged in an active review, a part of knowledge work, of the events of the hospitalization and those leading to the hospitalization. It is not known to what extent the review was stimulated by the interview, but patients and families seemed eager to describe and review what had happened and how they had managed. For example, "The doctor wanted me to go right to the hospital from the arteriogram. I said no. I knew I would have the surgery, my legs are my transportation. But I wanted to be ready. I was."

Reviews also focused on their most difficult moments: the day of surgery, right after surgery, and the downplaying of the seriousness of the problem and the procedure. At the time of the home visit one patient was still quite distressed by her hallucinatory episode during the hospitalization. She was crying, and under great pressure to review the episode and explain it. (Her son recommended that she try to see a psychiatrist. She tried to get an appointment with one through her health care plan, and was told that there was a three month wait.)

Families did some evaluation of their experiences and had some advice: "Drive people crazy asking questions." "Just understand what and why, ask questions, don't be afraid to ask. It's hard to ask." "Face it head on, get it over with."

Meaning was constructed for events as was evident from remarks during these reviews: "They made a mistake sewing me up," and "He was not with it in the hospital. I wasn't worried, I knew it was the medications," or "This all started because I quit smoking. That's when things began to go downhill." Integration work, to understand and incorporate the meaning and implications of the surgery, continues: "I'm still puzzled about how or why this happened." [What have you been told?] "Dr. W. said it was a clogged artery, the radiologist said hardening of the arteries. I still think it's caused by my trouble with the parathyroids, the calcium and all."

In their reviews, families described feelings of pride in how they had figured things out:

During the time that she was in the hospital, I didn't get to talk to the doctor. I had to piece together the facts, just out of observation. I found out I was right, when I finally did get the chance to ask.

They expressed pride in how they had managed without the need for outside help. A husband said: "I learned to cook, but more than that, I learned that we can manage without outside help. I'm really proud of that. We didn't even need a housekeeper."

Those who employed them reviewed their strategies for coping:

On the day of the surgery, he told me to stay at work. [Patient: It's uncomfortable, you don't know what to do.] She came at noon, after calling to see how things were going. The nurse said I could come over and wait in the lounge. I went right over, I couldn't stand it anymore. But he wasn't back until 3:30, it was a long, long time . . . We worked as a team, one step at a time.

The patient, a father, said:

I felt it was my responsibility to orchestrate everything for a good conclusion. The doctors see so many people, they can not keep track of everything. It was my responsibility, I am the one who has to understand things. I also guard against being psychosomatic, it doesn't help.

They discussed their shock, their surprise at the seriousness of the surgery:

This surgery was harder than the heart surgery, more pain and more weakness. It's harder to recover.

The doctors downplayed the seriousness, I found out her artery is near the backbone. I didn't realize, it was a shock to see her with all the tubes. I wish they told me.

I didn't expect it to be such a big thing. I didn't think it was going to be as big a deal.

and what they were proud of:

We did the right thing, we got this taken care of. The first doctor, he said he wouldn't touch me with a ten-foot pole, and that my chances were very slim. I said, 'what happens then?' He said, 'I watch you,'- and then I take your legs off.' I said, 'the hell with that, and with you, if that's all you can do.'

Relational work. In their relational work, the husband's statements of pride in the ability to manage role shifts and additional

tasks during recovery were accompanied by statements of expectations of and need to return to previous patterns of family functioning:

I'm cooking and cleaning, shopping. I cleaned the house once while she was in the hospital, then this morning. What is there to do? Just vacuum and wipe off the furniture. But, I will be so glad when she is well. I need her, and not just for this . . . I'm cooking, but you wouldn't want to eat my food.

Another husband said:

We're teaching each other lots of things, getting well and used to being home with new tasks and other kinds of things. It's really OK. I've learned a few tricks these past couple of weeks, like shopping, always take a list Actually, things are going to change around here pretty soon. The shopping, it's kind of fun, but that's stuff ladies know. I'll be happy to get back to work.

Wives and female family care takers did not express the same pride in their accomplishments. They had some complaints, however, and expressed the need to set limits, as in the illustration of the daughter who said the mother's demands were a headache, and "I can't get out, I feel so guilty when I leave him alone." "There's no time for me now, I need that time."

One wife's complaints reflected her attempts at health work, without sufficient knowledge or authority:

He's not going to cooperate. I just cried this morning. He is crabby and so insulting. He was sitting with his legs crossed. I said 'don't do that,' and he blew up. I had a feeling it would be like this. It's not my responsibility. I'll just help when I can. It's really been rough, there's not a lot of space here. I don't know if he is endangering himself. Before his walk, he wouldn't let me take his pulse. [Were you told to take it before walking?] Do you think his heart is OK.? It's just when you've seen anyone go through what he has, you want them to get the most mileage out of it.

In the families where the patients actively resisted the sick role, or where they acknowledged and tried to limit the demands on the family,

there was less conflict and less emotional distancing, caution, more ease.

During recovery, the family seemed to have come to the test, with some passing, some failing. One patient who was asked: "Do you feel that you got the support you needed and wanted from your family?," said:

Not really. At first they were there, then not so much. They began to make snide remarks, when they took me to the doctor, said they were using a lot of gas. I was hurt, but we were never that close anyway.

In contrast, a husband said he learned that his wife was competent and could be counted on, that "this is the first time we had a test like this in our marriage. . . . My family comes at the drop of a hat, we rally, it's great."

Families managed their concerns more openly and together or more separately and carefully, a difference in family coping patterns that became more apparent at this time. Only two patients made direct reference to their disease by this time in the interviews: "Well, I learned I have hardening of the arteries, I'm not pleased about that." and, "I know that this could come back, and that I can still lose a leg".

Health work. In terms of risk factor management, all patients and families displayed some knowledge of smoking as a major risk factor, although the specific mechanisms of the risk were not well understood. A patient was asked what he thought had brought about this vascular condition and illness. "They all say smoking, but I'm not a scientist." Another patient, who was better informed, said: "I know it's a good time to quit. The doctor told me all about it, how it affects the blood vessels, but so does stress. I get stressed without a cigarette."

Smoking was a focus of family concern and family conflict: "He had some before I got up. I hid them," and, "she just lights cigarettes and then puts them out when she is with me." Family members continued to smoke, with the exception of one wife: "I've stopped smoking. It's not good for him to have someone smoking around him."

The mother of one patient went outside of the house to smoke, and one patient's son stopped in an effort to help his father. Of the eight patients who were smoking before surgery, six resumed smoking after discharge. "Things are going great, all but quitting smoking. She's had some depression trying to quit smoking." The patient's lack of appetite was a concern for several families, and the return of appetite for many, at about this time, was seen as a symbol of recovery.

Psychological work. Health work was, as before, also mediated by psychological work. The family and the patient "held back" on calling the doctor with concerns and questions, preferring to wait and watch. The wife of one patient said: "The blood pressure is down, he tires real easily. . . ." The husband added: "and I have dizzy spells and spots in front of my eyes." [Have you spoken with your physician about this?] "No. It's really only when I get up at night. [Wife]: "It was awhile before he could move, but it hasn't been a problem since Saturday".

The "holding back" may be related to the family's need to feel competent and not to be a bother, as well as a fear of indulging the patient's symptoms. One wife complained: "This medication thing (too much pain medication) is a serious problem, and very difficult. It is something I cannot do for him."

Problems or questions about medications arose in two situations. In one, the patient said she never took the prescribed digoxin. When asked why not, she responded: "Because the morning of the discharge, the nurse said she felt leery about my taking it since I never took it before, and my pulse was regular." Her husband said he helped with that decision: "We both thought she didn't need the digoxin, since she was fine, and there was no irregular pulse."

In another family, the wife was concerned that her husband was taking too many pain medications: "He has a fuzzy head, staggers. He could stand a little more (pain). It's an area of conflict. Most of the time, I keep out of it." In the case of the wife's concern about the pain medication, she did not call the physician, or insist that her husband call, although she said: "The doctor doesn't know what he looks like." She "framed" the problem in terms of balance, and her need to keep a balance to promote recovery:

He has so much sympathy, too much. I have to balance, not too much sympathy, not to baby him. I know he hurts, but some people don't do well with too much sympathy. It's hard to balance, and be the bad one.

One illustration of many of the family's struggles and typical responses at two weeks is an interview with a wife of a patient recovering from an aorto-femoral bypass. She was interviewed at work. She said there was no time to schedule a home visit, since her [work] hours had been crazy, and she didn't get home until late.

[How are things?] He is very, very much on edge. [More than before?] He was sometimes short before, but it is constant right now. I didn't expect him to be so uncomfortable. He lays with nothing on his stomach. He is sensitive all along the incision, the hair is growing back and it is very sensitive. I wonder, is he focusing too much? Is something else bothering him? If it were me, I'd call the doctor. He wouldn't do that. The doctor said, 'Give me a call in a

month.' To me, that's too relaxed. [Would you consider calling?] No, unless it were an emergency. He is an adult, a grown man. It would upset me. He would be hurt. But I think he tends to underreact.

[How is your morale?] OK. Sometimes I have to remind myself that he has been through major surgery. You miss your husband.

The researcher asked about the impotence, identified in the admission interview as a major reason for the surgery. She said:

That is not improved. I haven't made an issue of it. I just say, you've been through a lot, don't fret over it. The doctor said before the surgery that this could be affected. When we went to the hospital for the arteriogram he said there were two procedures, one a cleaning out of the arteries, by all means preferable. Bypass can get infected down the line, it could cause impotence. A problem with the endarterectomy, the cleaning, is impotence from all the moving stuff around. The condition was much worse, he needed the bypass.

[I'm not sure I understand, which would cause or alleviate the impotence?] I didn't ask. I thought the doctor would bring it up. I didn't ask because I didn't know if J. wanted me to ask. Knowing J., he would want to ask the doctor. But he's cavalier, doesn't want to know, maybe. He said he had a partial erection, nothing to brag about. He said, 'Is this the best I can expect?' It was in the first week, the first few days of being home. He said it's not fair to you if that's all there is. I said, you couldn't walk before. Now you can walk. His expectations were that there would be an automatic recovery with the increased blood. He won't ask about it.

[You do not see that you could do anything, intervene?] No. If he were in pain, yes. But as long as he is fairly comfortable . . . he's annoyed that the other problem is not resolved.

This interview demonstrates the care that family members exercised, the careful consideration of their jurisdiction, the circumstances in which they would take action. Impotence for this 47-year-old patient was a major impetus for surgery. It is approached and then retreated from.

This wife echoed other families' statements about the concern with the need to balance, to guard against over-indulging the patient:

I don't spend enough time with him. I visit with the rest of the family, we don't spend enough quiet time together. I don't know what his needs are. They are mainly psychological. He is an adult. He can handle it.

[Do you sense an avoidance of psychological kind of care?] Yes. [What is that about, do you think?] It is not to indulge it. I don't want to make him feel like an invalid. I do pull back. I could go sit with him, and just have some quiet time, but I don't. I go out for a run, or visit with the rest of the family.

Home work at two weeks consisted of continuing the tasks of family life while allowing the patient to rest, to recuperate. Tasks were taken over, roles shifted, but the work is mixed with relational work; the call back to arms. There is pride in accomplishment, but with caution that it is not something that one would like to keep doing. Earning work is not given up, it is juggled to accommodate the patient's needs, i.e., coming home for lunch to check on the patient, going to work later, staying later.

Acknowledgment and Containment Strategies

Evidence of beginning acknowledgment of the presence of the disease process was the families' conflict over smoking at this time. Attempts to hide cigarettes and cajole and argue about smoking were now part of most family discussions for the patients who smoked before surgery.

Diet and exercise were more vaguely understood. Understanding of these two risk factors, in terms of vascular disease management was incomplete or non-existent. A patient replied, when asked about dietary regimen or change: "I don't know anything about a diet." When it was evident, risk factor management was approached without asking for

guidance, as if they knew how and what to do, in spite of failure and conflict.

Acknowledgement was also evident in some families' new sense of vulnerability and they worked to understand what had happened. As one patient said: "I'm feeling depressed and down right now, it's driving me crazy, I think it's the 'why me?' syndrome, feeling sorry for myself." And, "They think I'm delicate, they are being careful of me. I've learned not to do stuff that is bad for you."

A hint of the issue of sufficient alarm in the family's response to peripheral vascular disease as it might effect integration again emerged in a patient's remarks contrasting his aneurysm surgery with his cardiac complication:

When I found out there was more, I took it pretty good. [You mean the abdominal aneurysm?] Yeah, it was good they found it. But it was a real shock to hear they found a blood clot in my heart. That was something. I was really scared.

Containment at two weeks was evident in the family's retreat from the patient's demands, the expressed need for "balance" in giving sympathy, the caution about catering to, "babying" the patient. The increase in physical complaints, the unexpected, continuing fatigue, lack of energy, and emotional lability were managed by "living through" it, and not solicitously. Certainly, a therapeutic approach, a "going toward", (asking about) patients feelings was not in evidence. The families with more open communication noticed and acknowledged feelings, but even they did not "open them up" for exploration and discussion which might facilitate emotional integration.

Acknowledgement began as events were reviewed, pieced together, attempts made at clarifying, and as unexpected morbidities and shocks of

complications were confronted. Comments about the "downplaying" of the surgery were evidence of this kind of acknowledgement work toward family integration.

In their recovery assessments by one month after discharge, four of the twenty-one families were "over the hump" of recovery. The patients said they felt better, and described themselves as 100%, or 99% recovered. A few "small" (in the patients' words) problems remained, however, even for these, e.g., a spot on the incision not yet healed, the swelling of the leg not completely gone. The family had returned to normal life routines.

For the others, it was as one patient stated: "The surgery was a success, but the recovery was not a success." Complications of the surgery: wound infections, draining lymphoceles, swelling of ankles and feet, distal (great toe) ischemia, rehospitalizations, weakness, lack of energy, anorexia, and constipation, either had not resolved as expected, or occurred unexpectedly. Patients and families coped with disappointment and anger over these and other recovery morbidities: "I'm very disappointed, so disappointed that it has taken this long to heal. I can't get going. It [the operation] was supposed to be a simple one."

Negative meanings for these unexpected disappointments were constructed. For example: "I didn't listen very carefully when the doctor said it's the best hospital but someone has to be taught." One patient was facing (and dreading) a treadmill test for suspected cardiac disease, and very depressed: "I'm very depressed, not looking forward to anything, to going to the hospital for another test. About doctors, I feel like 'I love you but I don't want to see you again.'"

Depression was least evident in the more open, mutual families and with those who were more realistic in their expectations: "The way I see it, there's always tomorrow, don't worry over it. He's making a slow but sure recovery and I thank God he's here everyday." Other families not already "on guard" about the patient's demands or sick role behavior earlier now began to express their concern and retreat from a care taking role:

She's not getting going. She is still weak, but she just hasn't tried. If I lay around all day, I get weaker too.

She had two areas on her incision that opened up and were infected. She told me about it. I said you should call the doctor. She didn't. It was still running, and I found out. She said, 'I thought you would call.' I said, 'No, no, no.'

Another patient's wife expressed concern that she had pushed her husband too hard:

We got worried last night. I went shoppin' with a friend of mine, she asked him to put up a bed for her. It took too long, he gave me a yelling. And, he says I didn't leave him anything to eat, but there was a chicken leg in the refrigerator. He showed up to help with the bed, though. It took three times as long as he thought. Anyway, he finished it and he was real tired.

She had stopped catering to him, but was not sure about that.

The wife who was concerned about the amount of pain medication the patient was taking at the two-week visit affirmed her approach at one month:

That situation (of the medications) has improved. He is trying. He thought this bottle would be his last. He's uncomfortable and miserable, grunts and groans. It hurts. I can't do anything about it. Not too much sympathy, just enough.

Another patient's wife said:

I try to make time everyday, we talk. I don't want to make a baby out of him, create a monster. A young cardiologist gave me that advice a long time ago. He said S. can do anything he wants to. The illness was a big blow, a big mountain to climb, but we're doing it.

The time of acute threat seemed to be over for most, exemplified by this remark from one spouse: "I don't feel the same threat. Things are annoying, but not life threatening."

Patient morale was down from inactivity and disappointment. The family responded by pulling away emotionally. The least evidence of this phenomenon of "guarding" was seen in families in which the patient maintained his or her agency, or control and family role and who reciprocated the family's concern, resisted, or "shed" the sick role as quickly as possible. In two of the three families who most closely fit this description the patient was the husband, in one, the father.

Family work. Health work, relational work, knowledge work and psychological work were intimately related in the family's adjustment during recovery at one month. In most families, there was some stock-taking of the recovery progress, but many of the patients and family care-partners did this knowledge work separately, or at different times, expressing their concerns to the interviewer and not to one another. The families worked out a strategy for what could be said, what should be said or done, about integrating the illness into the family life, depending on their relationship with the patient, and without professional guidance.

In the one month interview a patient's wife expressed her concerns about his diet, disease (one of the few who did so) and her strategy for dealing with the topic:

The peanut butter thing, I said it's not good for your disease. I talk about 'your disease,' that may be cruel, but the doctor emphasized to me that he had to watch his diet to slow down his disease. [Nobody seems to focus much, talk about that, that there is a disease process, that the blockage is a part of that disease process.] I have to. But prevention is negative, the focus is on bad things. I try to say, keep up the good work, it's not easy. [Does J. know his cholesterol level?] No, no--not tested.

The daughter-in-law of a patient said:

Things are back to normal, pretty much except for the aneurysm. Should I get on his case about smoking? I don't want to nag, but he is smoking. [If you wanted more information about the aneurysm and the effect of smoking, how could you find out?] I could read Consumer Reports, or the Layman's Guide to Medical Technology, or I could talk to the doctor. It would be easier if I were at the hospital, to talk to the doctor. I know A. wouldn't care. We got all out information through A. He wouldn't lie. He's not the type."

Home work as an issue for family coping was greatly diminished, as the patient regained his strength and reclaimed his former role and tasks. (Where these were slow in returning, the family retreated.) When homework burdens were mentioned for those with still recuperating patients, it was accompanied by the family's concern or a complaint, signals that they are feeling the burden. This varied by family role.

One patient, a mother, whose recovery was complicated and slow said: "I am depressed, I was not depressed before this surgery, I am depressed and not eating. I am tired, I do not push myself, I am doing the best I can," and "T. is giving too much of himself." By her recognition or acknowledgement of his work, perhaps, she preempted his sense of burden (or only his expression?).

The family's health work at one month was concerned with helping the patient to deal with the emotional fallout of unexpected complications. Families' comments revealed some awareness of risk factors but the mechanisms or management of these were not well understood, (e.g., when asked about following a diet, a patient said he had to watch the salt, did not have to worry about fat, since he had lost weight in the hospital.) The family continued to operated without a sense of authority in their management. No family role had been constructed for risk factor management.

Relational work now seemed to be to constantly determine, or work out the extent and limits of their responsibility (as in the example where the family did not want to nag). Family activity in regard to risk factor management still hinged on the the primary factor of the relationship with the patient and avoidance of conflict.

In most cases, risk factors were primarily associated with surgical recovery, rather than prevention of disease. The idea of exercise as a preventive measure, or its connection to disease process, was not generally acknowledged. This is, perhaps, a fine line, conceptually, and perhaps too difficult a distinction for most patient and families to make at this point.

This limited, bounded definition of complications was, perhaps, appropriate in some contexts, such as that of continued incisional discomfort; but chest pain, swollen ankles, infection, weakness, slow recovery, transient ischemias, persistence of impotence, return of erratic blood pressure were a combination of a disease process in interaction with surgical recovery, and no patient or family member made reference to that connection.

Knowledge work at one month continued to concern the reconciliation of the surgical definition of the problem with evidence of continued morbidity. The patient and family had to cope with unmet expectations of an uncomplicated, speedy recovery. Continued or new complications were source of depression and anger. They were dealt with as isolated incidents, as a function of the surgery, and not the disease process, thus creating psychological sequelae, such as depression and a sense of betrayal, loss of confidence or trust in providers and family work to cope with these.

An interview with a patient who had a right renal artery reconstruction and a left renal artery angioplasty illustrates the shock of complications, the patient's work to understand and to deal with these, and the family's response at one month after discharge:

Everything is fine, except I'm disgusted with my blood pressure. The high blood pressure came back, sometime over the last week. I been to see my doctor twice. I'm shocked I had so much faith in that operation. [Have you seen the surgeon?] No. I'll see him next Tuesday, on my scheduled appointment. I talked with my doctor . . . what is that catheter that sucks out stuff? Can they use that? [Yes, if the blockage is due to atheroma, plaque on the vessel wall. Your situation is a little different, I think. Fibroplasia is a change in the vessel wall, in the shape and the openness, not plaque that can be scraped out.] Oh, I see. He said don't throw away your blood pressure medication yet. Maybe he was expecting something like this, something going wrong? [I don't know. He may have been just complete, knowing this was a possibility, that it might recur. I will call you after you see the surgeon, OK?] Fine, yes.

The researcher called the next week:

[So, what happened on your visit to the doctor?] He was surprised. I have another angiogram tomorrow. [Then?] He didn't say. He put me on medication for the blood pressure. [How are you feeling?] OK, a little shooting pain in my right side. He says it's gonna get better. [What is your guess?] I don't know. I'm a pessimist. High blood pressure is because your heart is pumping too hard? [No, not in your case. It's because there is not enough blood getting to your kidney, which has hormones to regulate blood pressure.] Oh, I see.

[How is R. (the husband) doing with all this?] R., he was a little sad yesterday. But he says, 'I'm not worried.' I asked him, he said, 'No, no, I will just take you to the doctor's and that's it.'

Families were still left to their own devices to evaluate and interpret symptoms, to decide to take action, and on what basis. They had not been advised of these complications (or warnings were unheeded or poorly understood) except in two cases, in which they were told to expect some swelling. They hesitated to ask for help.

Continuity of care was in the form of regularly scheduled follow-up appointments with the surgeon. The stretch of time between appointments with the doctor varied from bi-weekly to monthly visits; the majority had one month visits scheduled with the surgeon. As has been described, the patient and the family waited for these, rather than calling with questions. An interview with a patient, a diabetic, at one month illustrates some of these struggles, and how the patient and family manage and worry about one another.

[So, tell me, what's going on. T. said there's a problem with your toe, it's purple, and that you were over to see the doctor yesterday?]

Yes. The skin peeled off, it was bluish-purple. I thought, 'the end of the toe is dead.' The doctor at [medical center, surgeon] said he didn't know. The foot clinic doctor said to be honest, they didn't know, but it could be plaque or something blocking an artery from the surgery and I might lose the top joint of the toe, not enough blood going to the toe. It feels numb, doesn't hurt. The doctor at the foot clinic was just great, the only satisfaction was from them. He said to pat it dry, wrap it in lamb's wool, use open shoes. They gave me antibiotics. I went to the foot clinic first, and the nurse sent me up to the surgery clinic. He said he had no idea what it was. I went back to the foot clinic. There, the doctor said I might loose it at the first joint. Better to loose it there than the whole toe. I prefer the truth.

[Did T. (son) take you to the hospital, to see the doctors?] No, I took the bus. I didn't want to wake him up. It was something I could do myself. He said I shouldn't have. T. worries a lot, he is talking about not going to school, to work full-time instead, and that has me worried. I am tired. I am doing the best I can. I just don't push myself. T. never tells me anything. He is afraid it will upset me. He keeps everything in. He is in his shell. He still does everything for me and goes to school and to work. He is giving me too much of himself.

Two families had to apply sterile dressings and soaks for incision infections, health work of a direct kind. They mentioned these tasks, but took them in stride. There were no indications that they were not considered particularly stressful.

Only one patient referred to the graft or the possibility of graft failure, and had asked his doctor what would happen on the one month visit. "I asked the doctor if the graft would come apart. How would I know? He said there would be claudication and I should just get going, and forget about it."

Psychological work was now, as in the past, a part of relational work, the felt need to do a good job, to give proper care, but now also to balance, to guard against too much dependency or encouragement of the sick role. Psychological work was also the work of understanding, making sense of events and managing the feelings that result. When the patient was rehospitalized for his draining lymphocele a month after it first began, the patient's wife said, "Why didn't they think of this before? He's really mad." The patient, however, seemed resigned and calm. He said he had talked with the doctor.

He said he is worried about the kidney, can't take any risks with that. So I brought five books, and here I am, nothing else to do. I asked him who operated on me. He said he did, and Dr. (X) closed. That's OK, he's good. A chief resident, not one of the interns. It just happened, that's all, bad luck, that's all.

He asked his question, he got an answer, he didn't have to construct the answers. Called on the day after his admission, the patient said:

Dr. E. (the surgeon) is very unhappy. He yelled blue murder. They're supposed to clean out the debris, change the dressing three times, a doctor has to do it. No one has done it yet. This time I'm not going to hold it in, I'm mad.

He was angry, but taking action, and he now had an alliance with his surgeon.

Families continued to draw on knowledge of the patient for psychological management of the recovery: "No one has to tell S. to get going." or, "she was always like that, likes the attention, we had to watch that," or, "she's Yugoslav. They're tough."

The patient's disposition was a serious problem for one wife:

His disposition has been terrible, just awful. My daughter spoke with him about it. She said it was like wife beating, just as bad, as abusive. I think it scared him. He asked the doctor about it. He said it could be a result of the surgery.

[Is it dramatically worse, since the surgery?] Yes. He has not always been nice, but he was always in control before. He doesn't realize how abusive he's been, he didn't really realize. I think it's terrible frustration. He had this vision of the surgery restoring his youth, so unrealistic. Dr. S. told him that this operation was not the fountain of youth.

[What do you do when he is abusive?] I leave the house, or go to my room. When I come back, it's better but he never apologizes. The best thing to do is wait until it's over. He talked about seeing a psychiatrist, but he won't do it. He listens to my phone conversations, too. I have to be careful. I think he's listening now, I have to go.

The relationship between one mother and daughter in which the daughter "blew up" at the mother earlier was still "on edge" at one month. The daughter was away, visiting her daughter and new grandchild. "We haven't talked about it, I don't know if I can. There are oblique things, she sends cards that say I love you. The trust is still there, but she is more absent." The daughter said she did not feel closer; that she had been obligated and concerned, and now she was freer to be with her own daughter and grandchild, and to do what she wanted.

The husband of a patient reported: "She still have problems, her stomach is still sore, she is not up to par yet." Asked how her mood, morale were at this point, he said: "I am hard of hearing, it gets on her nerves. I'm doing a good job. I clean up, I go to work. I am going back to school, our daughter can give her breakfast." The patient said: "Sometimes, lately, I snap at R. for no reason. [What is that from, do you know?] "I really couldn't say."

Another patient discussed her family's emotional support and provided an eloquent summary of the interaction of relational, psychological, knowledge and health work for families during recovery.

They don't really understand what you go through. They are there to do things, but they do not understand how you feel, not like a real good friend can. A friend helped more than any family when my husband was dying, and helped him to talk. I couldn't.

[From talking with other patients and families in the study, there seems to be a kind of emotional distancing, avoidance of opening up feelings] Really, that's right. [What is it from, do you think?] They don't want to hear how you suffer. They are not able to handle it. I know the closer you are, the harder it is. Let's face it, they don't want to know, to see you in pain. They don't accept, don't want to make illness acceptable, they want you to get better. They are afraid to say, 'How are you today?' Everybody backs off. My brother says, 'Well, it's been eight weeks, come on, you have to be better,' like, 'I'm not going to indulge you anymore.'

Reciprocity and mutuality made a difference in the family's perception of the burden of care:

Oh, I don't mind staying here. If the shoe were on the other foot, he'd do it for me, he'd be happy to be here. I had a 102 fever, I was quite sick. [He said he took care of you?] Yes he did, slowly, and did he mess up the kitchen.

Again the question of alarm as a condition of the family containment arose in one patient's response to an interview question about whether there was any risk factor discussion with the physician or the nurse before discharge or on office visits. She said: "He [her husband] misunderstood one thing. When the doctor said the artery was like a tube of toothpaste, he thought he said 'tumor,' and he was really scared by that." The prospect of a tumor was more frightening to the patient's husband than the fact that her artery was like a tube of toothpaste.

Families remained fairly socially isolated in their management of recovery, although the contribution of adult children who were not the primary care takers was mentioned by now in three cases. In one, the son contracted with his father to quit smoking together, but was unsuccessful.

My son quit. P. was to quit at the same time. He did quit for that first day. You can't baby yourself, like an alcoholic, with a little, gotta have more. I smelled it, asked are you smokin'? Our son says that's so weak. He's so disappointed in him. Tells me, not him.

The daughter's involvement when the patient was verbally abusive and out of control has been described, and the daughter as new substitute for the husband who is going back to school is the third. One spouse said that her sister, who lived next door, came over if she needed her. Friends were not mentioned as resources for recovery.

Containment at one month was seen most dramatically in the families' "balancing" strategies in response to the patient's continuing demands and needs, and their apparent reluctance to provide emotional support. These patterns of interaction were evident before this time for many. Where the patient had regained or retained his or her agency, (power and control) in the context of reciprocity or mutuality in relationships, the family felt less guarded, or there was never a question of the need for balance. Containment was also evident in the separate, or private (unspoken) concerns of the family vis-à-vis the patient as they strategized about how to best handle recovery or information and the difference in the family versus the patient's appraisals of health and recovery.

A wider "split" became evident at this time between the families who had begun to confront the fact of disease and those who had not,

although many families were still approaching and retreating from awareness, acknowledgement, asking important questions, and then, stopping, and not pursuing the topic. The relative absence of confrontation with the facts of their disease, the continued lack of understanding, lack of clarification, and pattern of asking the interviewer and not the physician were other manifestations of containment.

Conditions that inhibited families in regard to "mustered" or "activating" themselves to manage the illness remained the same as during and before the hospitalization: their internal processes, social/situational convention, and the health care system's lack of outreach, or invitation. The additional condition at this time was that the family and patient were home, with only formalized contact with health care providers (between scheduled doctor's appointments). The role of unmet expectations regarding recovery, the confrontation with complications however they were defined can only be speculated upon, but these may have acted as catalysts for beginning work toward integration.

Three Months after Discharge

Recovery outcomes. Because it was the final research contact, the families' reports at three months are described here as as physical, psychological and family life recovery outcomes. At three months after discharge, the majority (13) of the patients described themselves as completely or almost completely (95% to 100%) recovered. In this group, however, everyone, even the "100% recovered" had some caveat, one or two "buts" or "except fors": "irritations", "nothing to do anything about."

Some of these problems were tiredness and weakness: "still so very tired", "can't wear shoes yet, still in Daniel Greens with the toe cut out," "a permanently swollen foot, I guess," "one episode of A-Fib, some numbness, tingling in the foot," "numbness on the bottom of the foot, but not the blood, that's fine, and the chest is still uncomfortable," "the incision still hurts a little," "the other leg is acting up now," and, "I'm down, emotionally."

Seven had enough complaints to give themselves ratings of 50% to 85%. Remaining or new problems and symptoms included: the return of high blood pressure for the patient who had a right renal artery reconstruction and (a repeat) L angioplasty; severe stomach ache and anorexia, extreme fatigue, impotence; muscle spasms, twitches, "good and bad" days, numbness in thigh; fear of new blockage at operative site, draining groin incision, no stamina, no energy, "wing" scapula and fluid under incision for the patient with post subclavian aneurism repair; incisional pain severe enough wake the patient at night; (new) severe pain behind R knee and R ankle swelling.

One patient (post AFBG) gave herself a "20%," saying she was still so upset over the "incident in the hospital [hallucinatory episode in the special care unit]. I can't stop thinking about it, I am still very depressed, my sugar is high, legs are swollen, bottom of feet are cold and stay cold. I can walk two blocks, but very slowly."

The recovery ratings and remaining symptoms at three months did not seem to be related to the patient's diagnosis, procedure, age, sex, or family role.

Integration. The family's understanding and incorporation of the illness into the life of the family can be inferred by evidence of risk factor management. Most families' understanding of the nature of the

disease process and the relationship of risk factors to illness management was vague by three months after discharge.

Six patients and their families were able to articulate a basic, more or less accurate understanding of the presence of a progressive disease process and the relationship of risk factors to disease development and management. Of these, one patient was following a preventive risk factor regimen of regular exercise, smoking cessation and low fat diet at three months post discharge. She attributed her activity and knowledge to discussions in the hospital with two nurses and to the fact that she is "not passive." (She was a patient from the site with a nurse clinician hired by the surgery group.) Her family's involvement was peripheral; encouraging and supportive. She was living alone by three months.

Another patient was not exercising, but had stopped smoking, and was aware of, but "not really sticking to," a dietary regimen of low fat. His spouse had been told by the surgeon on the day of surgery that: "It is important that he does not smoke, and he must change his life style, modify his diet." She had some knowledge of the disease before admission (that it was caused by smoking and heredity). One patient, who did not smoke before surgery, had not altered his diet and was unable to exercise or "get going" because of continued lymphatic drainage. Another patient who understood her illness was smoking again, after trying not to for the first six weeks after surgery. She said: "No diet, no exercise" when she was asked. One patient's diagnosis was retroperitoneal fibroplasia, and risk factor management except for smoking was not as relevant. He had stopped when the first symptoms of his illness appeared, five years ago. The family was quite well

informed about the illness and treatment, care and psychological/family coping.

One patient had stopped smoking, and described the need for exercise as "something I learned from this, the importance of exercise." He was not exercising, however. For dietary control he said he was "using less fat in my cooking." The last of this group was a patient with progressive and systemic disease, including severe cardiac involvement (post coronary bypass) and stroke, followed by carotid endarterectomies. She was well aware of the causative and preventive factors associated with her illness, and that her lifespan was limited: "I think about dying everyday, but I am nonchalant." She continued to smoke, although it "drives her husband nutty." She stated: "He tries to keep me on a diet, is more motivated than I am," but "I figure it is the quality of life. I'd rather live five more years satisfied than more, miserable."

Families of these six patients were well informed about the illness and preventive management. Only one of these, however, could be described as an active partnership in disease management, in which both the family member and the patient take responsibility and participate actively in disease management. Four were spousal families, one a mother and daughter relationship. Spouses were supportive and encouraging, but did openly share their concerns with the patient. In the last case, the patient described her family's involvement as: "We are partners in this experience." The partnership was in the acknowledgement of the disease, and the understanding of one another's position. The patient herself was not willing to change her life style: eating, exercise and smoking habits.

Several patients made "get away" remarks, like: "I've more or less forgotten the whole thing.", and, "Oh, I forgot all about the leg" in the three month interviews. Only one of this last group was exercising regularly, following a low fat diet and not smoking. She did not smoke before this surgery.

Families' and patients' levels of integration were generally parallel by this time, although there were indications in separate interviews that the family care partner may have felt less sanguine about the situation than the patient.

The family's involvement in recovery. The family's involvement in the recovery at this time was usually described as "minimal" or "nothing at all." Family recovery responsibilities or involvement this time, however, were both practical and emotional. The 18-year-old son was still taking care of the household chores for his mother: "T is here, helping everyday"; or the spouse who was "stuck" because her husband "just won't go anywhere"; a husband who encouraged his wife to "stop postponing and go back and do it right now" (second surgery if necessary) were examples. When it was acknowledged, involvement was described as: "I'm a good husband, I'm helpful." "Still checking things out," watching, encouraging. "He's pushing me on, does whatever I ask," and, "he tries to keep me motivated about the diet and the smoking."

The relationship between context of awareness and risk factor management was not clear. One patient who was well informed and aware changed her life style to include regular exercise, and low fat diet. She had stopped smoking when her husband died of cancer, four years before the surgery. One was very aware and had modified his risk factors with the onset of his disease five years ago. Two others were

quite aware of their disease, but not monitoring risk factors. Two were hampered by continuing health problems from exercising; one, who smoked, quit but neither had changed their diets.

There was no relationship to diagnosis, age, sex or family role in the pattern of risk factor management and contexts of awareness, although risk factor management awareness (six of six patients), and awareness of disease versus "contained definition" (five of six patients) was more consistent in the patients and families from the site in which a nurse counselled the families and patients at discharge as a part of routine practice. Three of the six patients from this site were actively engaged in preventive risk factor management.

Continued symptomatology was not generally attributed to vascular disease, but rather to the surgery. Feelings of anger, betrayal and loss of trust accompanied the continuing symptoms at three months after discharge. Those who were more aware of their illness were able to make some distinctions between the two. Symptoms were frequently conceptualized as individual phenomenon, and not associated with the disease process, including two diabetic patients who had both had coronary bypass surgery before this surgery. The manner in which symptoms were discussed (never in association or relationship with other symptoms) however, and the absence of risk factor management suggested a low level of integration.

Most patients and their families fell into a group in which their level of acceptance and their knowledge of disease was partial, pieced together without obtaining validation from providers, a kind of "passive-avoidant", approach. When asked directly about their

understanding, they made some connection: "the circulation is improved," "something to do with the blood flow, a problem with the blood flow," or, "I don't know, to make the blood flow easier. I never ask. The doctor went to school, that's his job."

The daughter of a patient who had a femoral artery reconstruction 8 years post AFBG said: "She's feeling great because the doctor said her heart was fine, she's not going to have a heart attack." This patient said no one spoke with her about prevention and risk factor management, but that she felt "well informed." One patient's comments demonstrated a level of knowledge of disease that discriminated between the two: "There is numbness in the foot, but it's not the blood, that's fine, the foot is toasty warm."

Family work. Relational work, the management of interpersonal relationships within the family and with providers and psychological work of identity management and performance control continued to mitigate against knowledge work for many at three months after discharge. The desire to be a "good patient," and not to bother the doctor (psychological/identity work) contributed to isolation, postponing and not obtaining information necessary for active, family-supported preventive health efforts.

Families felt helpless and distressed when the patient did not adhere to risk reduction advice, illustrated by a wife's comment about her husband's smoking: "Oh, God, he denies it, but I know he smokes. He empties the ashtray himself."

Interactions with physicians, part of relational work, followed earlier patterns. The rules of the health care situation, as interpreted by the patient and family, played a part in the apparent

lack of family health care action. The patient was given appointments for follow up and was hesitant, even loathe to call before or between these.

At three months, families maintained their patterns of postponing questions until the scheduled doctor's appointments or not asking questions at all, asking the researcher their questions, defending, rationalizing their behavior when asked if they had contacted the doctor: "I'm doing fine, really. I'll see him on the 15th, I'll ask then." When a spouse, who said she was "stuck" with the patient's moodiness and refusal to go anywhere or to be alone, was asked if she had sought help with any of these, she replied: "No, I'm coping on my own. He just has to get going, he's not back to normal yet." [Has the doctor seen your permanently swollen foot?] "The last time I saw him, it was swelling daily."

One patient explained his hesitation to ask questions like this:

The doctors and the nurses, but I should have looked things up, and I think I should have asked more questions. I didn't ask. I know he's a busy person. I don't know why I didn't, authority, I guess. I think, gee. I shouldn't ask. I should ask Dr. M. about the medication causing cataracts. One reason I don't is that I can always look it up myself. Sometimes doctors don't tell the truth, either. People expect them to know, so they say something. I feel like it's my own responsibility.

One interview is especially illustrative of the hesitation to clarify:

I'm wondering, I could get kidney damage, I think. I'm gonna talk to the doctor and find out how long I can have this (high blood pressure). I haven't lost faith, but maybe they didn't do enough for me. [What were you told when you went to the doctor?] To take the medicine. He said he's gonna do a blood test, a sophisticated test for hormones secreted, to see how the kidneys are, but he didn't call me back yet. [When was that?] A month ago. [Did you call him?] No. I didn't call yet. I guess if the angio doesn't work, they have to operate again? [You have to consult with your doctor about that.]

Listen, you know anybody I can talk to who has this? I'd like to compare, see how long I can go before surgery. Somedays it's OK, somedays way up. [You are the only one in the study with this kind of problem. Why don't you call the doctors, they can advise you. It's a good question.] I don't know. [Do you know that you can call the doctor with your questions? Just call and leave a message for him to call you, I'm sure he will.] Maybe I will try that, thank you.

One patient who had called her surgeon about incisional discomfort said, "I wasn't sure about that, I didn't want to bother him."

The only complaint, or remark from a patient about the "holding back" of sympathy which was a part of many family recoveries was: "Well, there's times I'd like a little more sympathy from my wife. I did not get much sympathy. When you hurt, you hurt, that's all."

Two wives (patients) said they were troubled by depression. When asked, they described how depression is handled at home: "I say, oh, gee, honey, sorry, it'll pass." "I still get depressed." [How does P. handle that?] "He doesn't know when I'm depressed. I don't say anything."

As the wife of one patient described a new crisis with cancer, she also spoke about her mother's surgery to have a fistula inserted in her arm for dialysis, which occurred during the same time period. Her management of a crisis with the surgeon illustrates the struggle to contain feelings, the need to carefully manage the relationship with the physician.

Oh, I saw Dr. G. again. My mother had to have a fistula inserted for the dialysis, and he did it. They underplayed that, said it would be about an hour, and it was five. [J. said he found out about the probable cancer on his one month visit, that the doctor had known since the surgery?] Yes, he called me at work. I said how did it go, he said I'll tell you when you get home. I said, 'What? Tell me now.' He said 'I have a growth on my lung, it's probably cancer.' I said 'you're not kidding, are you?' He said no, he wasn't.

I was so mad at the doctor. I thought, 'Why did you wait?' I was panicked. I woke up at night thinking about it. Then it got better. I was thinking that it was not the time to tell him, and maybe they did right. He couldn't have taken the surgery any earlier. I was going to call, then a week later I felt better about it. Later, I had another opportunity to talk to him (the doctor), I told him about the surgery. He said, 'Oh, I am so pleased to hear that he is OK now.' I asked him, 'when did you know?' He said, 'I knew the morning of surgery. I really had to make a decision. Logically, I should have stopped what I was doing. But we were all ready. I weighed the fact that it took him so long to come in and have this surgery. I knew he needed it, I thought to take the risk.'

He could have said he didn't know about it until after the surgery, that he didn't see them before the surgery. That's what I figured; that he hadn't seen them. He told me the truth. I was glad about that. And, things turned out for the best, they turned out all right. He said 'I did mean to tell you, but J.'s blockage and his condition were so much worse than we thought, and you were so concerned.' That wouldn't have worked. I couldn't hold on to that, J. and I don't work that way. He did the right thing. But it explains why he was so agitated when he came to talk after the surgery, so adamant about the diet and smoking. He never said anymore after that, or to J. Now I understand.

In their relational work, the return to normal was a loss for some who felt closer during the peak of the crisis and a new sense of vulnerability had brought some families closer together. The return to normal routines was seen as a kind of loss for some families. The "rallying" of the wife, husband, daughter or parent was enjoyed and there is a kind of ruefulness in the statements of return to normal. "She's gone right back into her old slump. She was right there for me when she thought I needed help, when there was a problem, but now that's over." In a separate interview, his wife said: "We seemed closer for awhile, but about the same as before now." Another said: "We are back to our old selves, back to normal." One daughter had another view: "I don't feel closer, I feel freer now. I was obligated and concerned." The "guarding" or titrating of sympathy and solicitousness so evident

earlier had diminished as relationships returned to normal and recovery progressed.

Family problem-solving relationships had not changed generally, although some change in the direction of a more open health care partnership was evident in two couples. One couple had to face another major crisis in the second month after discharge. The spouse said that she and her husband saw the doctor together this time. Separate interviews with this couple at three months had less of the spouse's individual concerns which she could not share, more references to "we," and the patient's open acknowledgement of the difficulties and stresses they both experienced. For the other couple, the partnership was described as a new discovery at the time of the home visit. Some felt closer because they had learned something about each other by living with and learning from conflict.

Knowledge work of review and evaluation continued for patients and families at three months. Although interviews encouraged this process, it seemed that ideas expressed were the product of some previous discussion and thought.

Review included a sense of closure: "I feel like it's over now. Mentally, it was a hard time for me. I had so much to handle, with children a job and my mother." Some reviews continued to deal with the unexpected distress of the surgery and the recovery: "If I knew how bad it was going to be I wouldn't have done it. I wish I had known what to do to prevent it, to live better."

In answer to a question about who or what was most helpful, most mentioned the nurses and the doctors, with a caveat or two, such as: "But I didn't really ask them," or "I should look things up." One patient's wife said:

The hospital really failed us in some way. We still don't like what happened, but he's well now, and we're not sure we want to write complaints. The (routine care unit) was wonderful, I can't say enough for the girls there, but I was angry. Others were in tears that day (of the surgery). Walking around, waiting during the surgery, having the desk clerk running down the hall to say the doctor wants you on the phone. I thought, what could have gone wrong already.

Other patients said: "In the hospital, the nurses could talk a little more, explain things. It only takes a few minutes," and, "I asked the doctors about activities before discharge. Nobody told me anything, just 'don't bend.' I wish somebody would have. I started thinking about the dacron* and I got really depressed. I bend over and feel like there's a knot in my stomach."

Strategies were mentioned in the reviews, such as:

I have a sixth sense about things; that helps, and keep going, look ahead.

The doctors and the nurses helped me, and before, with the heart surgery, the doctor said he didn't want to operate, I wasn't strong enough. I told him I had nothing to lose and everything to gain with that heart surgery. I was going to die anyway.

I took it one step at a time, like an alcoholic, and I'm more pessimistic.

There was nobody around to ask questions, no one to ask. Nobody is smarter than I am anyway. [What about the nurses, weren't they around?] I don't think they would tell me anything. The way I configure, nurses are so careful, can't stick their necks out, not in charge.

We prayed a lot.

* Only two patients or family members in the study made any reference to the prosthetic bypass graft, this one at this time, and another patient who referred to his "bionic" leg as better than his other playing tennis earlier. This patient had also asked the surgeon on a follow up visit if the "bionic leg" needed any special care or attention, and how he would know if it had come apart. No one else in the study expressed this concern. Graft failure after surgery may be so rare that to mention it to patients is viewed as unnecessary.

A couple of families who were more assertive and successful in becoming informed said they that there were no surprises. Others felt betrayed:

They say that I am cured, but I am not. I am not able to go back to work. I am going out on my legs, the diabetes and the heart. I was better off before the surgery.

I have learned not to trust doctors. He told me it could be longer than a year, I wouldn't have gone through it if I'd have known.

I haven't lost faith, but maybe they didn't do enough for me. Sometimes, I think they didn't do enough for me.

The whole operation was for naught. I feel very low, morale is very low, bad, I have lost my patience. [After his Doppler, the next day, his morale improved dramatically. He had thought that the bypass was blocked.]

[His wife]: He's turned the corner, but it took a lot longer than we thought. I took it one day at a time, like an alcoholic, I'm more pessimistic. He was impatient.

Some references to care received in the reviews concerned the downplaying of the seriousness or distress of the procedure: "If I knew how bad it would be I wouldn't have done it. I have learned not to trust the doctors" and "They downgraded the seriousness of it."

A sense of being set adrift, not getting the care or attention they would like was mentioned:

You know, it seemed so fast, a seven-hour surgery, nine days in the hospital, then he doesn't see me for six months. I want to know, how do you know everything's fine? I know I'm not OK, I've had to see people myself, take care of myself. A cavalier attitude. I feel like I have this bowling ball under my arm, it's big to me, a difference in perspective. The patient is set adrift.

There's a new pain in her leg, and no one seems to want to cope with it. They just say, 'Its not your heart.'

Part of the review was a new sense of vulnerability, "a new shadow," implying how the experience is being integrated:

There's a new shadow, that thing, how close we came, it's hanging over me.

We still have that uugh feeling when some little thing happens. I watch it when he picks up something heavy, but I bite my tongue.

We see how close we are to being no more, we realize how frail life is.

We have learned not to take each other for granted, not to take life for granted. I don't think it has still gotten into my head it was so scary. Hey, I'm not immortal. It's a shock. I might die. I'm vulnerable. Never take your health for granted.

If something happened to her it would be a terrible loss. I was scared to death.

I learned to take care of myself, it does matter.

The vulnerability was not precisely tied to chronic disease; rather to a sense of the surgery as a "close call" experience. This new vulnerability was more often expressed in families whose relationships were emotionally close, where there was a sense of mutuality.

At three months after discharge, the family had nearly accomplished or was striving toward a sense of normalcy, of return to normal life patterns, in spite of continued evidence of ill health and the physical and emotional sequelae of major surgery.

Psychological work of identity management was implied in remarks indicating the need for normalcy such as: "Oh, I forgot all about the leg," "I love you but I don't want to see you anymore" (referring to her doctor), "I've more or less forgotten the whole thing," and a wife's comment that their biggest problem at the present was that they needed a new refrigerator.

Health work at three months was examined in relation to the families' risk factor management and understanding/acknowledgement of the implications of the disease for the family's future. These have

been discussed under knowledge work and as a measure of integration.

For a summary analysis of risk factor management at three months, see Appendix D-2.

To summarize and elaborate, of those patients who were actively engaged in risk factor management, only one displayed accurate knowledge of the relationship of the risk factors to her disease, or peripheral vascular disease, as a chronic and progressive health problem. Another was simply following the recommendations of her physician and did not desire to know more. The rest of the patients approached risk factor management in a more tentative, even haphazard (half-hearted?) way, and ranged in terms of their developing awareness of underlying disease from partial/vague to none. Family involvement was mitigated by lack of knowledge and authority as well as the relationship with the patient. More than half the smokers continued to smoke. One patient and her husband were very aware and knowledgeable, but the patient refused to stop smoking and try to manage risk factors, stating that the quality of her life without her usual habits and style of living would not be worth it.

Since they had not been instructed in how to implement or devise a risk factor program, most patients made their own unique interpretations of what constituted risk factor management, e.g., playing tennis a couple of times a week, playing golf, gardening, using less fat to fry food. One patient attended a vascular rehabilitation clinic to learn how to care for himself. He did not discuss his program with his wife, and became more sporadic in his exercise the longer he was away from the supervision and support of the program, which lasted for four weeks. One patient set up his own regular exercise regimen of walking everyday, but regretted not knowing to go slowly at first.

Other than the diabetics, no patients or families displayed any knowledge of prophylactic care such as skin care, ways to prevent traumatic tissue damage, signs and symptoms of further circulatory compromise, the importance of reporting the recurrence of these signs or symptoms to the physician immediately, measures to maintain and enhance lower extremity blood flow (described as outcome criteria for intervention for recurrence of lower extremity complication in Dolye, 1984, p. 825).

Instructional materials about vascular surgery were available in two settings. Families referred to a vascular information booklet available in one setting occasionally, but rarely for recovery guidance. One said it was confusing in that regard, but not for risk factor management, although it was covered on the last page of the booklet in general terms.

Smoking cessation programs and guidance, dietary and exercise control information is available in attractive, easy to understand, inexpensive publications of the American Heart Association. In general, patients and families maintained their patterns of "configuring" at three months, although a few expressed feelings of being set adrift to fend for themselves with troubling symptoms.

Home work. In all but three cases, home work was no longer disturbed by recovery care demands. In the three cases, the patient was still disabled to the extent that the family was still taking care of the household tasks that he or she performed before the few months preceding the surgery.

The rhythm and routine of the home life had been re-established, although, for some, in an unsatisfactory fashion. The wife who

complained that she had to stay at home with the patient, since he refused to go out, said: "It's been so long, I don't know what normal is." Continued or intermittent depression and other emotional sequelae, such as anger and resentment, did not interrupt home work.

Containment Strategies

Containment was still evident at three months in expressions of the (implied) wish to forget, ignore, repair or escape an identity as a sick or recovering patient, the continued pattern of postponement and hesitation to obtain essential health information, to ask questions, clarify, or validate their own conclusions about their health or recovery on the part of the patients and the families. The evident need to cope "on their own" was, perhaps, a combination of containment (to keep the problems a family affair, to keep them from escalating by paying too much attention, or getting professional certification/attention) and a product of the psychological work of the need to maintain an identity as competent care giver.

Containment as a coping strategy began to disappear as symptoms continued and as anger and disappointment were expressed about the "downplaying" of the seriousness of the surgery and the length and distress of recovery. In the family relationships, the need to "contain" the patient's demands and "hold back" sympathy and concern was diminishing, although still evident. The diminishment of containment could also be seen in the new sense of vulnerability expressed by families and patients at this time.

Summary

During recovery, the patient's changing health status and the family's uncertainty in regard to these changes seemed to govern the family's responses and behaviors. Early family struggles were with emotional and physical sequelae of (unexpected) fatigue and weakness and other recovery complications. In one patient's words: "The surgery was a success, but the recovery was not."

Families were not prepared by their hospital experiences for a health care role after recovery. Families responded to the patient's complaints by emotional distancing and limit setting, as well as with concern and uncertainty. The patient's sense of betrayal by these unexpected morbidities and complications was shared by the families who seemed to have closer emotional ties and team-like relationships.

Acknowledgement of the presence of a chronic disease in the families' life occurred slowly and to varying degrees over the span of recovery to three months after discharge. Acknowledgement began as events were reviewed and pieced together. Comments about the "downplaying" of the surgery and recovery complications were evidence of this kind of work toward integration. Continued morbidities seemed to hasten or encourage the process of integration. Families and patients continued their patterns of figuring things out on their own and not seeking professional support during recovery, except in two instances early in the recovery: a wound dehissence and a very swollen leg and foot. Contacts with health care providers or resources were limited to regularly scheduled surgical follow-up appointments.

The family's work seemed to be to constantly determine the extent and limits of their responsibility. Family activity in regard to risk

factor management was in direct relation to their level of understanding and their relationship with the patient. Family health intervention efforts were uncertain and often a focus of family conflict.

The "surgical" definition of the nature of the health crisis for the patient and family predominated throughout the recovery, supported by strategies of containment in the family's knowledge work. Psychological work for patients and families contributed to containment strategies in the uncertain and distressing situation of recovery.

In the family relationships, return to normal routines was seen by some as a kind of loss. Families had rallied during the acute phase and "gone back into their old slump" by the late recovery phase. Some families had failed the test; the patient was bitter and disappointed by the family's response. Some were closer, brought together by a new sense of vulnerability and living through and learning from some family stress and conflict. A couple of new partnerships in problem solving were made.

By three months after discharge the majority of patients described themselves as completely recovered. Recovery was surgically defined; however, knowledge of risk factor/disease management was not a part of the patient's or family's definition of recovery. As an outcome measure, risk factor management provided a measure of family integration. Most families were not engaged in risk factor management of the patient's disease by three months after discharge. They demonstrated little knowledge of risk factors and methods of managing these. No study families had established what could be described as partnerships in this health care effort by three months after discharge, although a small minority of patients and family members had made self-fashioned, desultory attempts.

CHAPTER FIVE

DISCUSSION OF THE GROUNDED THEORY

Containment

Containment was observed in the family's non-confrontational, controlled and passive/opportunistic behavior and a "next-event" vs. future oriented approach to situations and problems associated with the illness, treatment and recovery throughout the time frame of the study. This pattern of regulation was observed in the families' interactions with one another, their health management behavior, their relations with care providers and others external to the family.

Ideal type is a concept constructed, derived inductively from the real world by the social scientist a heuristic device, "a measuring rod" to capture the principal features of some social phenomenon. They are not mirror images of the real world, but rather, one sided, exaggerations of a type, and are used in analysis to aid us in "making sense of the real world" (Weber, discussed by Ritzer, 1983, pp. 128-129.)

At first view, the data were not particularly remarkable: there was nothing especially dramatic in the families' stories. When one began to consider what the ideal case might look like, in the sense of family energy, activity, mastery of illness and clinical assistance geared to the positive construction and integration of the illness into the family life, the analytic story began to emerge. These families' stories never came close to that ideal. The data were remarkable, not for what the families said and did, but for what they did not do, and what did not happen.

In the family's limited, "contained" interpretations of the surgery and its implications for the future, containing the crisis worked to "protect" the family from the need to change to accommodate a chronic illness. Family change in terms of integrating, or acknowledging the illness in the families' lives, and risk factor management by three months after discharge was minimal. There were hints of a changed perception of life in a new sense of vulnerability, and for some, feeling closer, but the opportunity was lost to muster for the work of prevention, to learn about the disease and how to live with it. The role of the family as a source of support for change that must be made in life style was postponed or lost.

The notion of "tolerable doses", or the need to regulate distress is not new. It is being studied under different conditions and with different phenomena, such as Horowitz' (1986) intrusion and denial in stress response syndromes, Janis and Mann's (1985, 1977), Averill (1979), Lazarus and Cohen (1984) studies of vigilant versus avoidant coping patterns. This study may provided further insights into the role of the situation in the use of regulative coping patterns.

Conditions and Contexts of Containment Strategies

Conditions of the nature and direction of the family work expressed containment strategies over time and included:

1. the tolerance of the family system for change as indicated by the family's philosophy, history and culture, and the nature of the patient-family relationship.

2. the family's agency, that is, its capability and influence derived both from the situation and their own innate resources, one of these being a reciprocal partnership relationship. The data suggested that containment was more pervasive when the the patient and care partner did not work as a problem solving team, did not act together, or were less less open in their relationship. Where there was an absence of reciprocity/mutuality in the family relationship between the care partner and the patient (became when the patient did not act to limit the demands his or her illness created on the family, or when the patient exhibited signs of demoralization, such as depression, there was more containment. This was expressed as emotional distancing.
3. the presence, nature and quantity of clinical complications; the clinical course itself.
4. the rules of the treatment situation. Perceived rules dictated the nature of the family-clinician interface and interaction. Families' interpretations of situational rules, in turn, were the result of the relative absence of invitation to explore concerns and a comprehensive, rather than "next event", or event-by-event (contained) approach to the problem in the part of the patient, the family and the providers. (This was referred to in the field notes as: "The problem of care under the illusion of cure"). In the hospital, the family was without agency, without authority and influence, without "permission" to assert themselves, run things. The family "contained" its worries, in an effort "not to disturb"

the health care or the patient. Then they (often abruptly) took the recovering, diseased person home. The care jurisdiction changed, the family took the responsibility of care as a matter of pride and is loathe to ask for advice or assistance between scheduled appointments.

5. a sustained ambiguity surrounding the meaning of symptoms and the purpose of the treatment. The focus on a particularized definition of the problem as a lesion, without a great deal of attention to "a lesion from what?" and "what will happen next?", may have been a product of a "least damage" conceptualization on the part of participants: the surgeons, nurses, patient and family.

The focus on the surgical result is understandable in the circumstances of hospitalization for surgical treatment, and not unique to patients with peripheral vascular disease. But the (unchallenged) conceptualization of the surgery as a cure seemed to have preempted attention to care: the management of the disease causing the blockage. Mishel and Murdaugh (1987) discussed the family's adjustment to heart transplant as a process of "redesigning the dream" of cure and a return to pre-morbid health and life style. The "heart" family must be enlisted in the complex, delicate health management of the patient after surgery, but their adjustment to the realization of chronic disability and a delicate life threatening balance required time, effort and professional support. Parallels exist between the heart patients' families and families coping with surgery for peripheral vascular disease. The

difference for the PVD families was that they were not enlisted in the health care of their relative.

6. Family and gender role seemed to influence containment strategies. Access to information was more limited and constrained when patient was a parent. Siblings limited their involvement more than spouses, children or parents. When the patient was the wife, the husband exerted pressure to limit the sick role and return his spouse to normal role function. The husbands of the more chronically ill wives were more patient, and asked for less recognition and appreciation of their accomplishment of household duties, since they were more accustomed to these tasks.

When the patient was the husband, a wider range of accommodation of the sick role was evident. Wives were more indulgent and patient. They did not ask for recognition or appreciation although they complained of fatigue and restrictions imposed by the care taking role.

7. the particular nature of this illness: insidious; quietly building, and associated with aging, with deterioration. There did not appear to be an "illness imperative", or sense of alarm with peripheral vascular disease, in contrast to a diagnosis of cancer, or heart disease. Peripheral vascular disease is a "low profile" disease and rarely a cause of death in and of itself. Although present in advanced stages of the disease, no one in this study had visible stigmata of the disease other than their slow, shuffling gait. Limb loss due to the disease is more usually a last resort

after the disease has progressed for many years and after first efforts at treatment are quite effective, although not curative.

Related disease phenomena, such as stroke and heart disease can be a cause of sudden death, however. Perhaps it was not clear to the family, patient and or the clinicians what the correct and proper level of alarm should be for this problem at this stage. Certainly, there was no "all out" mobilization on anyone's part, except for those on "aneurysm watch", in contrast to the heart surgery patients, reported in Gortner, et al, (1988, in press).

8. Major life style changes to prevent or slow the advance of the disease require dedication and family change to restructure around the illness. For the patient and the family, this also requires identity change. The identification of oneself or of a family member as a chronically ill person may be resisted. Interpretations such as "clearing out the blockage", a "cure", are less troublesome.

The literature on the family's response to illness indicates that professional understanding of families' accommodation to serious illness must account for the family's need for normalcy (Anderson, 1981 Barbarin & Chesler, 1983, Thorne, 1983,). This may account for the wish to forget about the surgery, the resistance to change in life style for risk factor management reflected in one wife's comment that their biggest problem was that they needed a new refrigerator.

Strauss et al (1984) discussed the basic strategy, or "chief business" of chronically ill persons as "not just to

stay alive or keep their symptoms under control, but to live as normally as possible despite the symptoms and the disease" (p. 79). The wish to avoid the "identity spread" of illness to their other, intact capabilities may have been powerful enough to resist integrating the illness into the lives of these patients and families. A major coping task for the chronically ill (and their families) identified by Miller (1983), is that of maintaining a positive self concept.

9. The fact that the researcher heard complaints and concerns and family efforts to understand their situation that were not explored further with clinicians in charge of the patient's care may have been a function of the fact that the researcher was handy; she was around, she had time. She was listening, watching, asking questions and learning.
10. Pre-existing chronic illness (peripheral vascular disease in context of diabetes and/ or coronary artery disease) did not seem to alter the direction or extent of the use of containment. In the case of preexisting diabetes or heart disease, containment seems to have pre-existed this surgical event, generally. There were different levels of acceptance, of awareness, with different levels of family involvement; nevertheless, a "next-event", event-by-event pattern of management existed before this surgery in these families. In fact, the notion of "least damage" in these cases: to simply survive, to take care of the pain, to relieve the symptoms was more pronounced. They had more realistic, limited goals, and little family involvement in risk management.

11. These patients were all adults, with adult family roles and functions. This may also have contributed to the family care partner's containment of a more active role in health care in the hospital and after discharge, in deference to the patient's agency.
12. The lay perspective of these patients and families may account, in part, for the family's lack of assertiveness or involvement in the patient's care. The frame of reference on which to base questions or concerns may have been too fragmented and incomplete to mount a participatory role in a situation which did not encourage it.

The Grounded Theory's Fit with Extant Theory and Research

The theory of containment and family integration constructed from the data of this study of family responses and adjustment to surgery for peripheral vascular disease supports and dimensionalizes the major theoretical framework of family stress and coping, the Double ABCX Model (McCubbin & Patterson, 1986) in several respects.

The first of these relates to the importance of the "C" factor: the family perception of the stressor event and the total family situation in relation to the stressor, and its interaction with "B": the family's crisis meeting resources, or vulnerability to crisis.

The family's generally bounded and particularized (contained) definition of the event of vascular surgery served to ward off crisis and major family disruption. The family's and (to a greater extent), the patient's "surgical" focus, a product as well of the context of

surgery and recovery certainly, was not (generally) challenged or interrupted in interactions with clinicians to a sufficient extent to cause alarm, to create a crisis which would require family change: a new level of family adaptation.

Family resources, the "B" factor, seemed to account for the variation in families' the use of the strategy. Few families in the study called upon external resources, i.e., friends, neighbors, community services for support. Most were essentially isolated. Their isolation may be considered an effect as well as a contributor to containment. Internal resources: family esteem, communication, problem solving, mutuality, flexibility, seemed to dictate the strength, or pervasiveness of non-reactivity, non-activity and isolation/self containment on the part of the family. Families with more mutuality and open communication contained less. Families whose relationships seemed strained by poor communication and isolated coping efforts contained more. The complexity of family relationships observed in families of either of these contrast groups, as one observed the families over time left one with appreciation for the individual and family strengths that possessed by even the most non-mutual and isolated families.

Containment was also perceived as a family and individual strength. The social situation also contributed to family containment. The families were uncertain bystanders in an "unscripted" arena. Keeping "cool", and not disturbing, figuring things out on one's own, were perceived by families as positive efforts at proper performance. Family interpretation of cues given by the health care providers: the authorities and experts in the situation, did not encourage or invite family action or involvement, although it seemed that providers were

receptive to family inquiry and participation when the family involvement was self initiated. The relative contributions of the social situation or context and the family's internal resources in the interface: a health care crisis, need further study.

In their report of the use of family self help groups to mediate stress associated with treatment for hypertension, Storer et al, (1987) described the application of the Family Adjustment and Adaptation Response (F.A.A.R) Model, a refinement of the Double ABCX model, and also developed by McCubbin & Patterson, (1983). Briefly, the model hypothesizes three critical stages in family adaptation: a) resistance, or denial and reluctance to admit that family change is necessary and inevitable; b) restructuring, the process of making structural and behavioral changes and c) consolidation, or the resumption of stable internal functioning.

Hypertension treatment involves behavioral and or life style changes which disrupt family functioning. The authors observed in family observation and interviews that this disruption stresses family members individually and as a whole, and constitutes a major obstacle to compliance with regimens of health care. There are strong parallels in the nature of the disease and the need for family change in both peripheral vascular and hypertensive disease. In fact they are often related disease phenomena. Hypertension is a known risk factor in peripheral vascular disease.

The authors suggest that crisis is necessary for family restructuring to accommodate the new (anti hypertensive) life style, but that this crisis is rare without some resistance to the structural change. Resistance usually takes the form of family-wide denial of the

seriousness of the condition which allows the family to function normally for a time, but at increasing health risk to the hypertensive. Another time limited adjustment can occur in which blood pressure is temporarily controlled with minimum of effort by taking medications but making no other life style changes. (This would be parallel to the patient undergoing surgery to revascularize a blocked artery). Side effects and expense of the medications eventually lead to a reversion to denial or enough disruption to begin restructuring. (A recurrence or continued morbidity and disability in spite of the surgery may bring the family to begin restructuring). Knowledge of the disease and the seriousness of the disorder were the two best predictors of patient compliance in a previous study cited by the authors (Caplan, Robinson, French, Caldwell & Shinn, 1976). In the project reported, these two factors were increased by enlisting the extended family's support. The extended family was enlisted as "information broker" by designating one member as a Volunteer Hypertension Health Counselor, who receives and disseminates accurate information to the family and provides a safe forum, with understanding of the cultural and personal competencies of the questioners for the family to learn about the illness and its treatment.

In the F.A.A.R. model, information was seen as the single most important variable in determining the nature of the meaning and coherence, (definition) of the situation. Belief in a successful treatment outcome was essential and an outcome of accurate knowledge and the support of the family. Eustress, or positive stress must be introduced into the family system to motivate treatment compliance. The positive stress was provided in the form of family mobilization.

A major conclusion of this hypertension study is that the most beneficial time to intervene is not the restructuring stage, when the family has already expended many of their energy and resources on resistance, but "when intervention hastens the movement of a family to a state of crisis by increasing the hardships associated with diagnosed but untreated hypertension" (Storer, 1987, p.314), by providing the knowledge and support resources to cope with a treatment regimen, and get the family through the (necessary) disruption.

Containment strategies were interpreted as the family's means of resisting change, staving off disruption. Seen through the framework of the F.A.A.R. Model, strategies of containment could also be a result of insufficient knowledge of the disease and the seriousness of its consequences without life style change. As has been suggested earlier in the discussion, the strategy may well have worked in a circular, or progressive, fashion; as both a cause and an effect of the family's isolation and lack of support which would introduce the positive stress to allow change.

Miller (1983) studied the coping patterns of chronically ill patients to discover effective coping strategies. The coping behaviors were categorized as approach or avoidance strategies, following the coping styles work of Lipowski, Lazarus & Cohen, Goldstein and others. She found that the approach strategy most frequently used to deal with tasks of chronic illness had to do with seeking information, and that denial repression, suppression and minimization the most frequently used avoidance strategies. She concluded that judgements cannot be made about the value of approach versus avoidance strategies unless criteria for effective coping are used. Coping is effective if uncomfortable

feelings of anxiety, fear, grief or guilt are contained; hope is generated; self esteem is enhanced; relationships with others are maintained; and a state of wellness is maintained or improved. It would appear that both approach and avoidance are in the service of effective coping at different times. Perhaps in their efforts to reduce emotional discomfort, maintain hope, self esteem, (unchanged) family relationships, and conflict free relationships with clinicians, these patients and families sacrificed a state of wellness.

An extensive study by Pratt (1976) tested the effectiveness of the energized model of the family in performing essential health care tasks and functions. Among these functions was effective interaction with the health care system. Characteristics of the energized family included member interaction in a variety of contexts, varied and active contact with other groups, active work to cope and master their lives, (seeking out information, taking the initiative), participatory decision making, and responsive and tolerant family relationships.

Pratt found none of the features of the energized model as a dominant American pattern, and that the health care system itself worked to lower the family's potential capability to act on its own behalf by being prevented from developing knowledge, skills, judgment, confidence and responsibility for their own health care. Her findings coincide with those of this study of families coping with peripheral vascular disease. The restricted flow of information in the hospital culture, with two thirds of patients given no instruction about care after discharge, she concludes, effectively takes them and their families out of the action. Specialization of care also contributes to fragmentation in care delivery, another way that families are kept out of the picture, or capabilities reduced.

In this study, fragmentation of care was evident. The surgeon became the primary physician, but his or her focus was the repair of the lesion, revascularization. Three patients were visited by their primary care physicians during their hospitalizations. It was evident that attempts were made by the surgeons and by referring, primary physicians to discuss the disease and its management, because the patient and family demonstrated at least a partial, and sometimes more than partial understanding of the illness and even risk factor management. The understanding was not enough, however, to overcome resistance to change. Pratt's finding that characteristics of the energized family are not dominant in the American culture may help explain the pervasive containment in this study. If family assertiveness, initiative, participatory decision making and so forth are not a part of our cultural, norms, then families need a push, our invitation and welcome to participate in health care.

These data support other studies' findings that effective vs ineffective coping must be assessed on the basis of the fit of the family's strategies with a complex field of forces and the family's collective consciousness (Thorne, 1983). The more active "partnerships" were not sufficient to ensure a positive integration of illness and illness management into the family's life.

CHAPTER SIX

ANALYSES OF THE FAMILY MEASURES

Analysis of the three family measures were performed to examine change and difference in patients' and family members' scores over time, from admission to the hospital (time 1) to two weeks after discharge (time 2). Four separate statistical analyses using two tailed, paired t tests were performed on each of the family measures. These were: analysis of difference in patients' scores from time one to time two; analysis of difference in family members' scores from time 1 to time 2; analysis of the difference in patients' and family members' scores for time 1 and time 2. The level of significance was set at ($p = .05$). A summary of the descriptive statistics is displayed in Table 4.

The overall risk of at least 1 type I error with this number of tests is: $P = 1 - (1 - .05)$ to the 56th power, or 94%. The significant findings are discussed in light of the qualitative findings.

Reliability Analyses of the Family Measures

Cronbach's Alpha internal consistency reliability analyses were first performed on all family measures, for both the patient and family members at time both time points. Analyses were made using only those subjects who had complete data on each instrument.

Cronbach's alphas' range at the two time points for patients and family members for the APGAR was .83 to .94. For the FIRM I it was .81 to .97; for FIRM II: .82 to .88. The alphas' range for the FIRM social

Table 4

Means, Standard Deviations and Ranges of Family Measure Scores at Two Time Points

	PATIENT						FAMILY									
	TIME 1			TIME 2			TIME 1			TIME 2						
	<u>N</u>	<u>MEAN</u>	<u>S.D.</u>	<u>RANGE</u>	<u>N</u>	<u>MEAN</u>	<u>S.D.</u>	<u>RANGE</u>	<u>N</u>	<u>MEAN</u>	<u>S.D.</u>	<u>RANGE</u>	<u>N</u>	<u>MEAN</u>	<u>S.D.</u>	<u>RANGE</u>
<u>APGAR</u>	20	17.8	4.3	(2 - 20)	19	17.0	3.2	(10 - 20)	17	15.3	4.0	(8.0 - 20)	18	15.9	5.0	(3 - 20)
<u>FIRM</u>																
I.FIFS	19	2.4	.69	(.7 - 3.0)	18	2.4	.39	(1.2 - 3.0)	17	2.4	4.2	(1.4 - 2.8)	17	2.4	.59	(1 - 3)
II.FIRS	20	0.8	.47	(.05 - 1.8)	19	2.2	.40	(1.6 - 3.0)	17	2.0	.51	(.89 - 2.7)	18	2.0	.45	(.95 - 2.75)
IV.FISD	20	1.6	.36	(1.1 - 4.6)	19	2.0	.53	(1.1 - 3.0)	17	1.7	.59	(.57 - 2.6)	18	1.1	.62	(.7 - 3)
<u>F-COPES</u>																
FCASS	20	2.9	1.0	(1.1 - 4.6)	14	3.0	.98	(1.7 - 4.6)	17	2.8	.98	(1.3 - 4.4)	16	2.5	.97	(1.0 - 4.1)
FCREF	20	4.3	.5	(3.2 - 5.6)	14	4.3	.40	(3.8 - 5.0)	17	3.9	.76	(2.7 - 5.0)	16	4.0	.86	(2.1 - 5.0)
FCSSS	20	2.9	1.2	(1.0 - 5.0)	14	3.0	.98	(1.7 - 4.6)	17	2.7	1.4	(1.0 - 5.0)	16	2.7	1.46	(1.0 - 5.0)
FCMF	20	3.2	.58	(1.6 - 4.2)	14	3.1	.85	(1.8 - 4.2)	17	3.0	.83	(1.6 - 4.4)	16	2.7	.90	(1.4 - 4.6)
FCPA	20	2.2	.86	(1.0 - 4.0)	14	2.2	.92	(1.0 - 4.0)	17	2.2	1.0	(1.0 - 4.3)	16	2.1	1.20	(1.0 - 4.3)

desirability scale was .19 to .82 (.19 = patient, time 1). On the FCOPEs, alphas for the subscale "Acquiring Social Support" were .86 to .89; "Reframing" subscale .69 to .90; "Seeking Spiritual Support" subscale: .88 to .96; "Mobilizing Family to Seek Help": .03 to .72 (.03 = patient, time 1); and "Passive Appraisal" alphas range was .44 to .80 (.44 = patient, time 1).

In the major study analyses of the family measures no statistically significant findings had reliabilities of less than .61, ($r = .61$ to $.94$). Reliability analyses results are presented in Table 5.

Analyses of Change in Family Measure Scores Over Time

Patients' Scores

In the analyses of change in patients' scores on the three instruments from time 1 to time 2 there was a significant rise in the FIRM II subscale from time 1 to time 2 (time 1, $x = 0.8$ time 2, $x = 2.2$, $p = 0.000$, $n = 19$).

This subscale measures three dimensions of personal and family resources: a) sense of mastery over family events (fate control, flexibility, managerial abilities); b) family mutuality (emotional support, togetherness, cooperation); c) physical and emotional health. The dramatic rise in the patients' scores from time 1 to time 2 most likely reflects the acute uncertainty and poor physical health experienced by the patient before surgery and the relief, optimism and family support experienced during the early recovery.

In all but one case, the surgery itself was a success (one angioplasty failed and had to be repeated, but not until two months

Table 5

Coefficient Alphas for Family Measures at Two Time Points, in Admission (Time 1) and Post Discharge (Time 2)

	PATIENT				FAMILY			
	TIME 1		TIME 2		TIME 1		TIME 2	
	ALPHA	(RANGE OF INTER-ITEM CORRELATION)	ALPHA	(RANGE OF INTER-ITEM CORRELATION)	ALPHA	(RANGE OF INTER-ITEM CORRELATION)	ALPHA	(RANGE OF INTER-ITEM CORRELATION)
<u>APGAR</u>	<u>N = 20</u>	.94 (.65 - .95)	<u>N = 19</u>	.83 (.19 - .76)	<u>N = 17</u>	.92 (.56 - .87)	<u>N = 18</u>	.94 (.70 - .90)
<u>FIRM</u>	<u>N = 18</u>	.97 (.50 - .94)	<u>N = 13</u>	.92 (-.20 - .94)	<u>N = 13</u>	.81 (-.51 - .91)	<u>N = 14</u>	.93 (-.09 - .93)
I.FIFS		.88 (-.43 - .84)		.82 (-.43 - .74)		.82 (-.44 - .77)		.86 (-.57 - .90)
VII.FISD		.19* (-.64 - .70)		.82 (.09 - .71)		.80 (.01 - .67)		.82 (-.39 - .96)
<u>F-COPES</u>	<u>N = 20</u>	.88 (.11 - .73)	<u>N = 14</u>	.89 (-.27 - .88)	<u>N = 13</u>	.88 (.04 - .86)	<u>N = 15</u>	.87 (.03 - .92)
FCASS		.83 (.22 - .86)		.69 (-.30 - .71)		.86 (.00 - .83)		.90 (.07 - .90)
FCREF		.88 (.46 - .88)		.94 (.63 - .96)		.89 (.01 - .73)		.96 (.77 - .98)
FCSSS		.03* (-.32 - .33)		.72 (-.14 - .80)		.56 (.01 - .73)		.61 (-.18 - .45)
FCMP		.43* (-.21 - .58)		.73 (.05 - .62)		.77 (.24 - .61)		.80 (.26 - .73)

*In the major analyses of the family measures no statistically significant findings had reliabilities of less than .61 (r=.61 to .94)

after the hospitalization). Although many patients and their families were coping with unexpected post operative morbidities and recovery complications at time 2 (two weeks after discharge), they were back home, back in control of their own lives and routines, and making their own decisions. The surgery was over, and hope for complete recovery was strong. Their families had "rallied to their side" and were still involved in caring for them. Family routines were still disrupted to some extent, and the family was beginning to feel the burden of added tasks and functions, but these feelings were not shared with the patient. Although complaints escalated at two weeks disillusionment had not set in, and a sense of "the worst is over" predominated. Depression was present, but it was not a focus of concern and not being dealt with by the patient or the family. Perhaps the contained, "surgical" definition of the illness also played a part in this result, contributing to the patients' optimism and relief and sense of mastery at two weeks after discharge.

Family Members' Scores

In the analysis of difference in family members' scores on the three instruments from time 1 to time 2, family scores dropped significantly from time 1 to time 2 only on the FCOPEs subscale, "Mobilizing the Family to Acquire and Accept Help" (time 1 $x = 3.1$, time 2 $x = 2.7$, $p = .0429$, $n = 19$).

In the qualitative analysis of interviews and family observations, families appeared hesitant, almost loathe, to call on professional providers for assistance, to ask questions or to validate their assessments. The qualitative data seemed to explain this finding and to

reflect the family's sense of isolation and lack of support at this time as well as their contained coping style. There seemed to be an assumption of rational home care on the part of the providers, who left the family alone to manage with a minimum of instruction or guidance, and the family may have taken this as a cue for their proper management and behavior in recovery. The finding may additionally reflect the fact that the families were tired and "refractory" after the ordeal of hospitalization.

Analyses of Difference in Patient and Family Member Scores at Time 1

At time 1 (admission), there were significant differences between patient and family scores were present in the APGAR and the FIRM II subscale. On the APGAR, item 3, which measures satisfaction with the way the family responds to wishes to take on new direction and activity patients' scores were significantly higher than those of the family members (patient $x = 3.6$, family $x = 3.0$, $p = .0276$, $n = 16$).

This finding is interesting in light of the fact that at admission, the patient was quite disabled by his or her illness or at extreme risk (as in the known aneurysm patients). The patient may indeed have felt more freedom than the family, who had accommodated to the increasing disability over time, and compensated for the patient's losses. The family may have felt more "tied down" by the patient's increasing need for family assistance. The family may also have been anticipating the restraint of the impending hospitalization and surgical recovery.

On the APGAR item 5, which measures satisfaction with the way the family shares time together, the family scores at time 1 were

significantly lower than the patient scores (patients' $x = 3.4$, family $x = 2.9$, $p = .0235$, $n = 16$).

Again, it seems that the family was less satisfied with the quality of family life at the time of admission. The difference may reflect the increasing limitation of family activity because of the patient's illness and disability as well as the current situation for the family at time 1. The overall APGAR difference (patient $x = 17.8$, family $x = 15.3$, $p = .0352$, $n = 16$) would appear to reflect the general theme coming from the observational data of the family's dissatisfaction with family life at the present.

A "close to significant" difference in the family and patients' scores on item 2, which measures satisfaction with the way the family talks things over and shares problems (patient $x = 3.6$, family $x = 2.9$, $p = .0519$, $n = 16$) contributed to the overall APGAR difference and may have reflected the relative difference in the patient's and the family's freedom to complain at the time of admission.

In the FIRM subscale II, (Mastery and Health), the family scores were significantly higher than the patients' at the time of admission to the hospital, time 1 (patient $x = 1.0$, family $x = 2.0$, $p = .0001$, $n = 16$.) This difference is most likely a reflection of the patient's poor health, uncertainty and helplessness as upon admission to the hospital for surgery. Observations and interviews suggest that the family is still accommodating, and may be relieved that the patient is about to undergo treatment and is in good hands.

Analyses of Difference in Patient and Family Scores at Time 2

The differences in the patient and family APGAR and Firm II scores disappeared at time 2, two weeks after discharge. The family scores were up slightly for the Apgar item 2 ($x = 2.9$ to 3.1), the patient scores went down slightly ($x = 3.7$ to 3.3), and for the overall APGAR, the family scores rose (from $x = 2.9$ to $x = 3.3$). For the FIRM II, the patient score increased dramatically (from $x = 1.0$ to $x = 2.2$), while the family scores stayed the same ($x = 2.0$ from $x = 2.0$). On the FCOPEs subscale "Acquiring Social Support", the patient scores were significantly higher than the family scores (patient $x = 3.0$, family $x = 2.3$, $p = .0406$. $n = 13$).

Most families in the study did not have or depend on an extended social network of support. The three Black American families in the study (two of whom did not complete the FCOPEs at time 2) and who expected and welcomed social support from an active, involved extended family and social/religious networks were exceptions. During the home visit interviews (time 2) they described coping strategies which limited dependence on others (pride in self reliance, self sufficiency).

Patients were asking for and receiving social support: encouragement, information and advice as a part of their sick role. Friends called, sent cards, visited, but no such support or attention was available for the family members who were working hard to keep the family life functioning while caring for a convalescing patient. In one of the Black families, the main care provider, the daughter, complained a number of times that she had "to carry the ball" for the mother's care and that support was not forthcoming from other family

members, such as her brother. The work of recovery belonged to the primary care taker, the spouse or the other family member, a daughter or a mother who was there, self designated, from the beginning. In terms of the theoretical analysis, it was contained. A spouse may have complained about being stuck at home and unable to get out, but she did not ask for assistance, even from her daughters who lived nearby. The family member did not ask for help, and struggled along. This finding suggests support for the theme of containment. The FCOPES Reframing subscale showed significant differences in the family and patient scores at time 2; the patient scores being higher (patient $x = 4.4$, family $x = 3.8$, $p = .0493$, $n = 13$).

This subscale measures positive beliefs as resources, as well as the use of positive reframing, defining problems in a positive way. The difference at time 2 is accounted for by a very slight drop in the family scores from time one and a small rise in the patient scores from time 1. Home visits revealed that the patient was feeling "strong" and positive, even victorious at time 2 in that he or she had "shown that he or she was strong" (a question in the subscale) by accomplishing the surgery and getting back home.

A major finding in the qualitative analysis was that the patients and families did not do the knowledge work (nor were they specifically or adequately assisted in the task by providers), to define their illness as a progressive disease and to undertake the health work to prevent its progression. Both the family and the patient, but the patient more so, maintained the surgical, "contained" definition of their health problem as primary, although there were indications that they had some idea that there was more going on. They defined the

problem in a "positive" way, as a cured "blockage". "Facing problems head on", one of the subscale question items, may have been interpreted in light of the contained definition, getting the blockage opened, having the surgery, versus the problem of chronic disease, which was not faced "head on". Families had more realistic assessments, doubts and concerns, but did not openly share these with the patient.

A significant difference in the FCOPEs "Mobilizing Family to Acquire and Accept help" subscale, with patient scores higher than those of the family: ($x = 3.2$, family $x = 2.6$, $p = .0273$ $n = 13$) at time 2 is congruent with and related to the other significant finding of the drop in the family scores on this subscale at time 2. Two weeks after discharge, the patient was still a patient, "enjoying" the patient status, entitled to professional assistance, although the patients in the sample primarily used scheduled follow up appointments for medical supervision and were hesitant to call the doctor with questions. By now, the acute, peak phase of recovery was over. The patient was back home and under his or her own and the family's jurisdiction. Families did not feel predisposed (or encouraged by invitations) to call providers with their concerns and questions, and were additionally restrained by their consideration for the patient's feelings and need for control. The family did not seek assistance for themselves, on their own on behalf or on behalf of the patient, even when the situation was extremely upsetting and difficult. A few family members outlined the circumstances under which they would take independent action to seek help and those were all physically defined (if he or she were in great pain, hemorrhaging, etc.). Confusion as to assessment of surgical outcome for impotence, acute depression, risk factor management,

recovery activity guidance were not among these circumstances. Families expressed pride in their ability to do a good job, to do what was necessary, to hold things together, and to maintain the family as a self-contained system.

Results of the analyses are presented in Figures 3 through 8, along with the standardized norms where available. The norms for the FCOPEs scales were established with healthy college students, so do not provide a valid comparison group. The FIRM and the APGAR norms were established with families coping with major health problems.

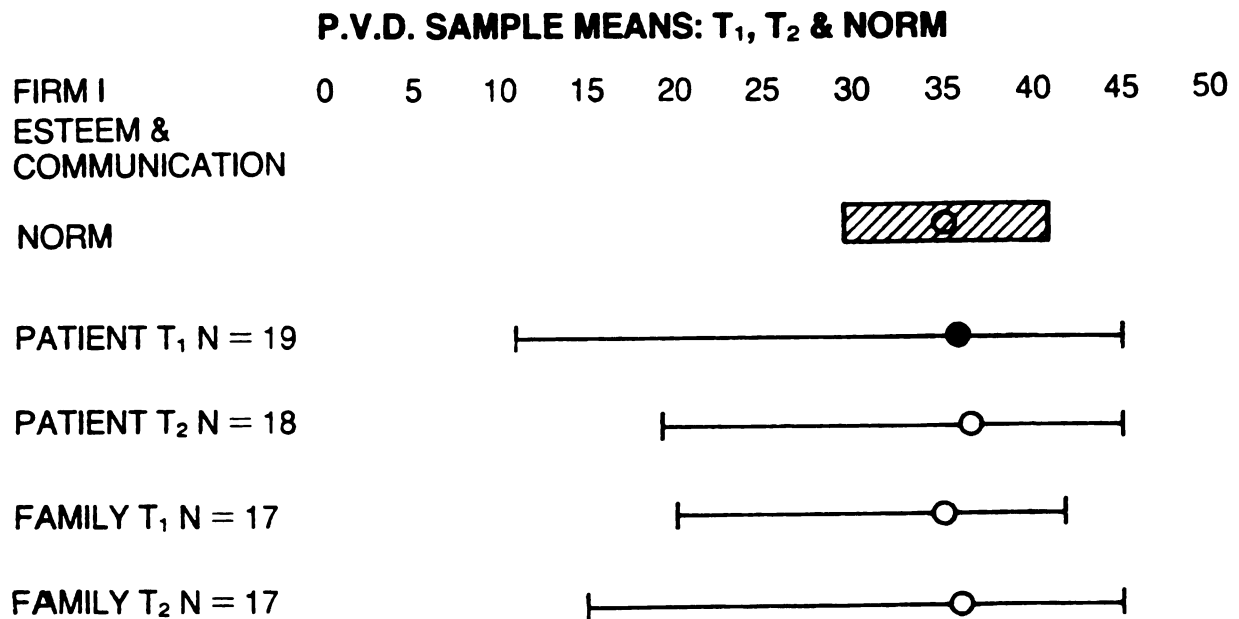


Figure 3. Results of the analyses: FIRM I

P.V.D. SAMPLE MEANS: T₁, T₂ & NORM

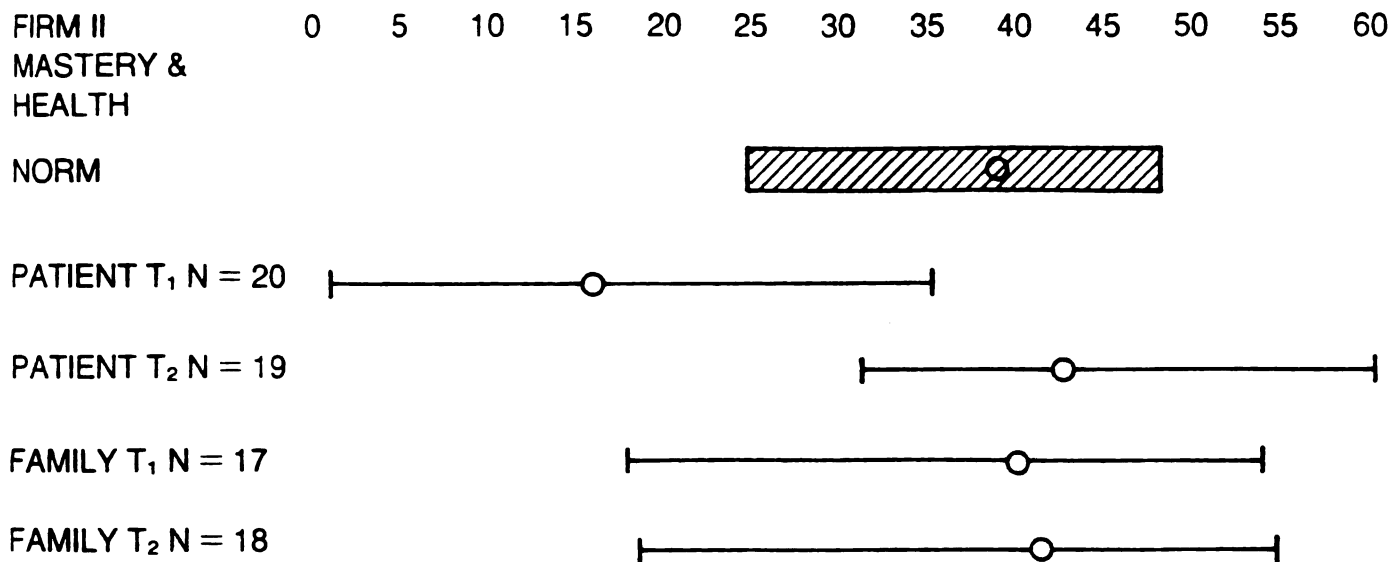


Figure 4. Results of the analyses: FIRM II

P.V.D. SAMPLE MEANS: T₁, T₂ & NORM

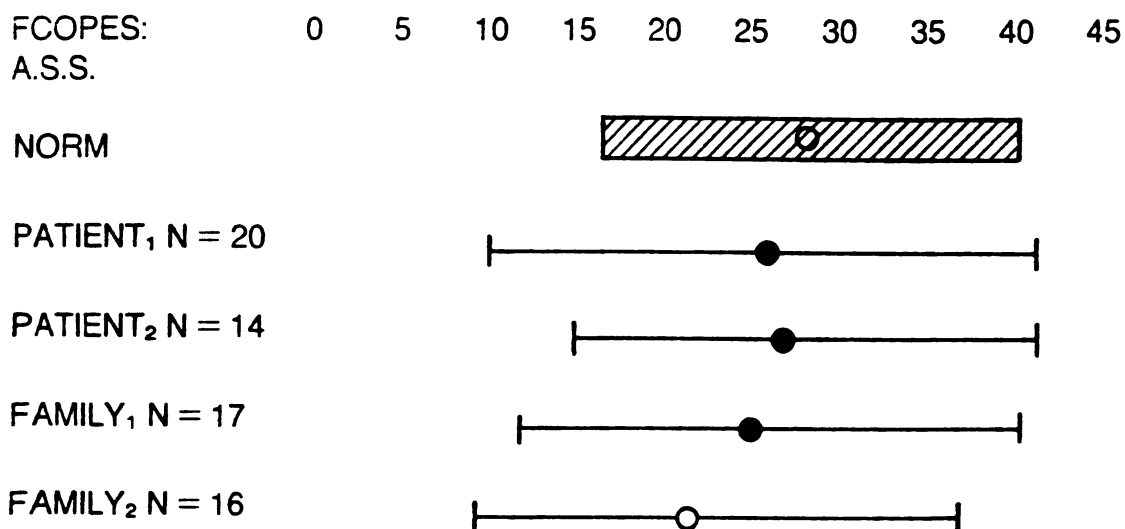


Figure 5. Results of the analyses: FCOPES: A.S.S.

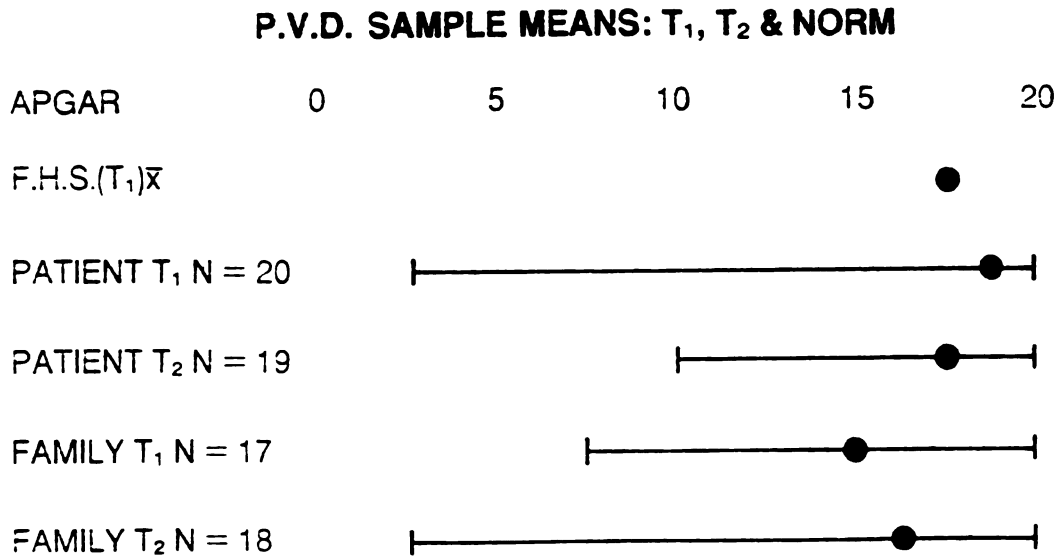


Figure 6. Results of the analyses: APGAR

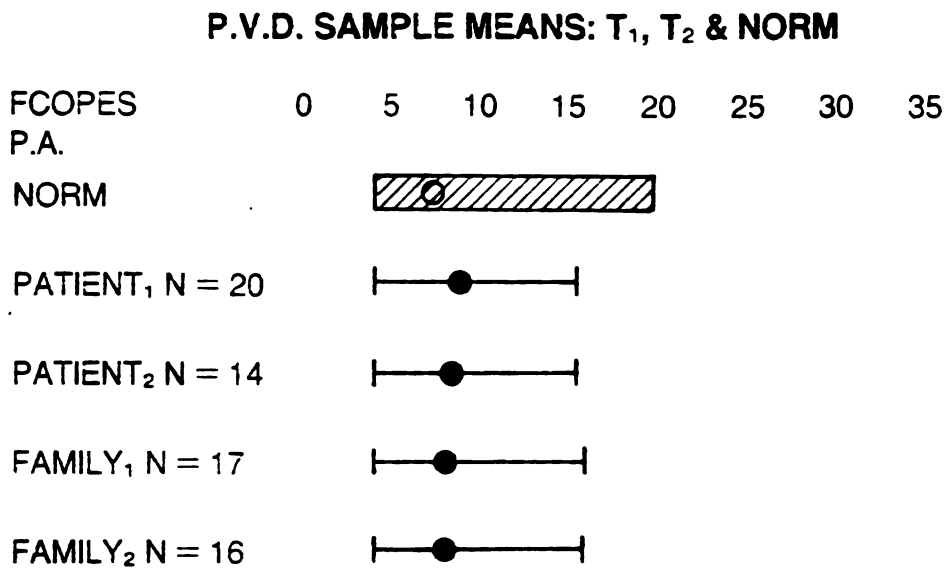


Figure 7. Results of the analyses: FCOPES: P.A.

P.V.D. SAMPLE MEANS: T₁, T₂ & NORM

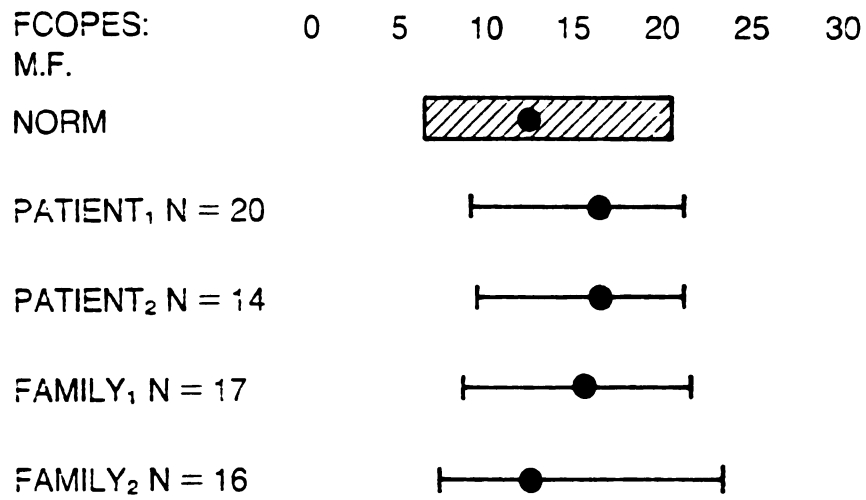


Figure 8. Results of the analyses: FCOPES: M.F.

CHAPTER SEVEN

ANALYSIS OF COMBINED FINDINGS

Comparative analysis of the family measures and the field observations and interviews was carried out by conceptually relating the statistically significant family measures findings to the observational data at the two time points. The theoretical framework of the grounded theory was used to interpret the family measures' results. This comparative analysis was included In Chapter Six.

To accomplish the methodological aims of the study, namely, the empirical validation of the three standardized measures of family coping and function, a case by case and instrument by instrument analysis was performed. Analysis worksheets were designed so that each subject's patient and family scores could be displayed in a table on the left half of the sheet with space for comparison with the observational data on the right. A sample worksheet is included in the Appendix B.

In addition, each subject's scores for each of the instruments at the two time points were displayed on analysis work sheets in vertical rows in order to compare the individual case with the group results as reflected in the mean scores used in the statistical analysis. The purpose of this procedure was to determine whether the time 1 individual case (subject by subject) scores were predictive of time 2 scores. Difference (family vs patient) scores as well as change scores (difference over time) were examined for each family instrument.

Results of the Validity Assessment of the Family Instruments

The APGAR

For the APGAR, low scores, (patient's or family member's) as well as discrepancy between the patient and family scores at time 1 did predict low scores and continued discrepancy at time 2. This finding was based on a score difference of at least three points, and a score below 15 at time 1. In two of the eleven cases which met these criteria, a bias toward "harder grading" was apparent on the part of the patient or the family. The low scores and the discrepancy did not match the observational data of the same variables. The high scoring, low discrepancy patients and family member pairs at time 1 were consistent at time 2 and their scores validly reflected observational data of the variables.

Low APGAR scores for either family or patient did seem to "tap" poor family function and poor family communication, based on comparisons with the qualitative data for these family function dimensions. The low (i.e. both family and patient scores below 15), higher discrepancy (more than three points on the scale) families on the APGAR were those in the study who appeared to experienced more conflict and isolation in their efforts to manage the crisis.

The FIRM

For the FIRM I, low scores (five points below the standardized norm mean of 35) and discrepancy in scores of more than five points at time 1 predicted low scores and continued discrepancy at time 2 except in one case in which the patient's score at time 1 rose 25 points to equal the family score at time 1 and time 2.

There were six cases which met these criteria at time 1. Of these, only one had lower scores for both patient and family at time 2 with the exception of one case with a dramatic rise in the patient's score. The remainder of patient and family member pairs had no discernible pattern. One case was negatively biased, (the same "low scorer" from the APGAR), and one additional case had no time 2 data because the patient was undergoing cancer surgery at the time.

The FIRM II results could not be analyzed for predictive validity due to the general (and statistically significant) rise in patient scores from time 1 to time 2, attributed to the change in the patient's physical health status from the time of admission to two weeks after discharge, and interpretations of the situation at the two time points: a shift from helplessness and uncertainty at admission to relief and optimism after discharge.

Eleven of the family scores were at or above the norm means at time 1. The lower family and patient scores corresponded to the qualitative data for the variables measured by the FIRM II. All the family patient pair's scores increased at time 2, even if only by a point. The families with low time 1 scores stayed about the same.

Discrepancy between patient and family scores as has been noted, is explained by the patient's illness. The FIRM II seemed to capture the effects of ill health in patients awaiting treatment. The fact that the family scores were not affected may indicate that the subscale does not capture the variables as family phenomena.

The FCOPEs

On the FCOPEs twelve cases had patient or family scores five or more points below the norm for the subscale Acquiring Social Support at

time 1 and all but 2 of these were highly discrepant. Two cases had family member data. The time 2 scores were relatively consistent with the time 1 scores where data were complete, in that the time 2 scores were also below the norm.

Acquisition of social support, as measured by the FCOPES, seemed to be a relatively stable attribute. Those cases with low scores on this subscale stayed low and high scores stayed high across time. "Reframing" subscale scores on the FCOPES seemed to correspond consistently to the observational data of family problem solving. Family member scores were generally lower than patients at both time points.

There were two cases in which the family or patient scores were low and discrepant at time 1 but appeared to be quite successful, characterized by open communication, role flexibility and partnership in managing the stresses of the hospitalization and recovery. In these two cases, the patient's scores rose at time 2, 10 points for one and 6 points for the other. Both patient and family scores were quite low at time 1 for a family who managed poorly, and both sets of scores rose to the norm mean by time 2. Family scores were low, patient scores higher (8-9 points above the norm mean) at time 1 for three families in which the spouse seemed to be more practical and realistic. In all, eight subjects of twenty had consistent and congruent scores across time; the rest were inconsistent, incongruent and difficult to interpret against the qualitative data. The statistically significant finding of higher patient reframing at time 2 seemed to be a result of a few dramatic rises in patients' scores and drops in family scores, one by 18 points.

"Seeking spiritual support" as a family coping measure was consistent across time, (high scores at time 1 were high also time 2) and there was correspondence with the observational and interview data. Three couples had very discrepant scores, but these scores were consistent over time. It would seem that spiritual support is a stable coping resource, but not necessarily a family resource from these data. Fourteen of twenty families had scores well below the standardized norm.

"Passive appraisal" FCOPEs scores, which measure the family's ability to accept problems and minimize reactivity, generally corresponded to observational and interview data. The least passive families had the lower patient and family member scores. Larger discrepancy scores seemed to be associated with families displaying more conflict and isolated coping patterns. Discrepancies in ranges between patient and family scores increased from six to twelve points from time 1 to time 2, but with no discernible pattern that could be based on the qualitative data. In the observations of family and patient behavior, passivity and efforts to minimize reactivity were prevalent in both patients and family members, but this was not as evident in the family scores. Change scores at time 2 on this variable's construct did not reflect a higher use of this coping strategy. Some scores dropped, others rose.

"Mobilizing family to acquire and accept" subscale family scores were lower at time 2 than time 1 and significantly below the scores of patients at time 2. The scores seemed to be valid in comparison with the observational data.

In summary of the FCOPEs' assessment, Acquiring Social Support subscale of the FCOPEs seemed consistent over time and reflected this

sample's behavior for this variable. The relationship between the FCOPEs' Reframing scores and situational behavior was unclear, while the subscale Seeking Spiritual Support was a stable but individual coping pattern judging from the observational data. Passive Appraisal measured on the FCOPEs revealed more inconsistency in scores and change in scores than anticipated, and did not strongly reflect the use of "wait and see", "watch and wait", hesitant coping patterns shown by most of the study sample; although the few consistently low scores were valid reflections of the more active patients and families in the study. The Mobilizing Family to Acquire and Accept Help subscale was a powerful corroboration of the qualitative findings.

Validity of the Family Measures in Tapping Family Behavior

The FCOPEs

A clear pattern for prediction of effective coping, based on the family's use of certain coping strategies did not emerge in an analysis of the FCOPEs. More study of this instrument along with direct observation family behaviors during situational crises and in relation to crisis outcomes is needed to validate this family measure's usefulness as an assessment tool. The external resource management subscale scores on the FCOPEs (social support and help) were generally true to the observed data. Four families had higher scores than the patients at time 2 for the subscale Mobilizing Family to Seek Help". These were exceptions to the general and significant finding of lower family scores at time two. The difference was not great, but in two cases, the family was quite isolated. In the other two, the family was

somewhat more open to getting help when they felt they wanted it than others. Three of the cases with low FCOPEs Passive Appraisal and Reframing subscale scores were among the more effective in gathering needed information, problem solving, and had the more open "partnership" family relationships.

The APGAR

The APGAR seemed to predict satisfaction with family life in five dimensions across time and validly discriminated between those families with more conflict and poor family function and those with better function, using low scores as well as discrepancy between patient and family scores at time 1.

The FIRM I low scores and discrepancy in family member and patient scores at time one were predictive across time but with less consistency than the APGAR. The FIRM II seemed to be an excellent indicator of ill health in the patient and relief after treatment, but not of the family's responses to treatment. Further, it appeared that the definition of the health problem can affect the FIRM's scores over time. In this study although symptoms were alleviated, the patient's understanding of his disease was incomplete and unclear two weeks after discharge when the FIRM II was reappraised. It seems that the alleviation of symptoms alone raised the FIRM II scores to well above the norm in the absence of a clear understanding of continued disease, although this inference bears further study.

In the comparison of the family measures with the field observations using a case by case analysis, the APGAR corresponded favorably to the observational data for most patients and family

members. In two cases the scores were lower than expected, (both in the patient's and the family's scores), based on knowledge of the family's interaction and problem solving. One patient was a "hard grader", with a generally negative bias on all instruments. The other low patient and family scores were surprising. This finding suggests that instrument data are, perhaps, more valid than inferences from behavior and statements made in interviews, especially in the measurement of a subjective and private dimension of family life: one's satisfaction with it.

The FIRM

The FIRM I subscale, measuring family esteem and communication appeared to have had a positive bias when compared to the qualitative data in three cases, for both the family and the patient scores in two cases and for the patient's score in one case. Where there was divergence in the patient and family scores the qualitative data supported the divergent finding. These were families who did not share their feelings and who were more or less emotionally isolated from one another.

The FIRM II was skewed due to the patient's illness and surgical definition of the problem, discussed previously along with the results of the statistical analyses. The only patient whose score at time 1 was above the norm, the sample mean and his family member's score was the youngest male in the study. He may not have perceived himself as helpless and uncertain in spite of his illness. He was quite frightened at admission. He was not verbally expressive about his feelings at any time during the study, and his coping pattern was one of acting strong. He also had a high "Reframing" score on the FCOPES at time 1.

Discussion of the Combined Analyses

The study aims concerned assessment of change in family function and coping patterns in relation to a major health event and processes contributing to family change. Hypotheses were not tested; although a major theoretical framework's (the Double ABCX Model) assumptions and constructs were, examined in the circumstances of this study, i.e., the family stress of major surgery in the context of chronic disease. In this study, the statistically significant results constitute an important, valid and reliable statement about the families' stress and coping with surgery and hospitalization even without the dimensionalization of the family's experience contributed by the qualitative study.

Contributions of the Family Measures

The unique contribution of the family measures to the study was the generality or statistical significance of change in patients' and family members' scores on the measures of family function, resources and problem solving from admission (time 1) to two weeks after discharge (time 2).

Family measures examine specific variables or theoretical constructs of interest which may not be "caught", or directly assessed by more open ended methods. The family APGAR measures satisfaction with family life, a proxy measure of family function. This added a meaningful dimension to the analysis.

In this study, the patients' scores on the Mastery and Health subscale of the Family Inventory of Resources for Management (FIRM)

differed significantly from the families' at time 1. This result may indicate that the subscale does not detect a family level process, or that the individual's uncertainty and poor physical health at the time of admission to the hospital is far greater than the family's. Thus, the measure's construct validity as a measure of family process was brought into question. Alternatively, this finding may stimulate further refinement of the measure or its fit with the theoretical model. It was possible to identify problem areas for families, deficits in coping resources such as a lack of mobilization to acquire help, a lack of social support, but without a specific substantive tie to the family's experience or the nature of the health problem.

Contributions of the Qualitative Study

The separate contribution of the qualitative analysis was the construction of an explanatory framework for the process of family adjustment to the event of surgical intervention for peripheral vascular disease. A dynamic formulation of the family's major coping strategy under the changing circumstances and interpersonal and situational contexts and the consequences of that strategy were constructed from participant observation and interview of families in the hospital and at home. The qualitative study demonstrated the use of containment and the various manifestations of containment in response to stresses throughout the illness trajectory, from events leading to hospitalization to three months after discharge. The maintenance of equilibrium and stability, (or, the resistance to change), seen in the family's emotionally contained, non-confrontational, internal interactional patterns and in their interactions with care providers was striking. Contributions of

the health care situation to the family's strategy were observed, as were consequences in terms of the family's non-integration of the illness, their relative absence of "taking hold", or mastery of health care tasks.

The qualitative study detected the threat of family distress, understated, perhaps, in the family measures' results through the strategies of containment. The family's work to stave off disruption, to contain the crisis, the ubiquitous depression and emotional distress of the patient in recovery, and the family's defensive posture in dealing with these psychological features was evident in the interviews and observations of family behavior in the situation.

Without the grounded theory, it was possible to know that the families were not mobilizing themselves to acquire help during recovery but without a clear understanding of the explanation or the consequences of this finding. How families gathered information under the circumstances of this study, the restraining forces in this aspect of the family's health work became evident. The family's identity and performance control, the (relative) absence of invitation to become involved and to participate on the part of the providers were unique contributions of the observations and interviews.

Risk factor management, the family's knowledge and participation in preventive health care maintenance to slow the progress of a chronic disease was identified as a major substantive outcome of the study, a measure of the integration of this surgical event into the life of the family. This and the other substantive aspects of the problem under study, i.e., the type of illness, the nature of the surgical intervention and the families' and patients' experience of the results

of the surgery provided explanation, dimensionalization and meaning for the constructs of family function and resources. These substantive issues were brought into focus and "grounded" as a result of the qualitative analyses.

Contributions of the Combined Analyses

Together, the combined yields of the different methods provided cross validation for the separate findings. One point of convergent validity of the two methods was the differences in the family's and patient's scores on the APGAR at admission (time 1), with patients significantly more satisfied with the family's response to their wishes to take on new direction and activity than their families, more satisfied with the way the family spends time together, which corresponded to the conceptual formulation of the qualitative data before admission to the hospital: family accommodation to the patient and his or her advancing illness. Another was the significantly lower family score on the FCOPES subscales "acquiring social support" and "mobilizing to acquire and accept help" at time 2, with a significant drop in the family's scores from time 1 to time 2. Both of these findings support and strengthen the containment strategy explanation of the family's coping. The higher patient "reframing" FCOPES subscale scores at time 2 may reflect the qualitative data of the patient's contained, surgical definition of the problem and the family's slightly more consistent, realistic assessment which they did not share with the patient.

A major finding in the qualitative analysis was that the patients and families did not do the knowledge work (nor were they specifically

or adequately assisted in the task by the care providers) to define their illness as a progressive disease and to undertake the health work necessary to prevent its progression. Both the family and the patient, (and the patient more so, maintained the surgical, "contained" definition of the illness as primary, although there were indications, as time went on, that they had some idea that there was more going on in the disease process.

This study's results support the family's definition of their situation as the key to understanding their responses (Knafl, 1985; Schwenk & Hughes, 1983). The significant difference between family and patient scores on the Family Inventory of Resources for Management (FIRM) subscale of mastery and health at time 1 and the dramatic rise in the patients' scores at time 2 were explained by the patient's surgical definition; the optimism and relief and sense of mastery that the surgery was over and had a good result, in spite of complications and psychological sequelae.

CHAPTER EIGHT

SUMMARY, CONCLUSIONS AND IMPLICATIONS FOR PRACTICE AND RESEARCH

Summary

This study examined family function and patterns of coping with major vascular surgery and recovery for twenty one patients and their family care partners. In the grounded theoretical framework, the concept of containment explained a variety of family and patient behaviors in the context of the threatening and ambiguous situation of peripheral vascular disease, its surgical treatment and recovery. Analysis of the data suggested that the family and the patient engaged in a process of crisis management and integration of the event of vascular surgery by employing strategies of containment as they progressed from the pre-hospital, illness development phase through surgery, hospitalization and surgical recovery.

Concern for cost containment and technological advances in treatment have shortened hospital stays, bringing about a subtle shift in the burden of care to the patient's family. Families must cope with the crisis of hospitalization and assume responsibility for appraisal and care of recovering, chronically ill patients after discharge.

Standardized measures of family problem solving and functioning exist. It was not known whether these would be valid predictors of these variables and stable over time or if these would detect families at risk in early, pre-crisis assessment in this clinical situation. In addition, the measure's capacity to assess effects of the crisis on family coping and function was of interest.

Subjects were recruited from three major urban hospitals on the evening of admission to the hospital for surgery. They were followed in a longitudinal study design from admission to the hospital until three months after discharge.

Instrumentation was combined with grounded theory as a triangulated method of accomplishing the studies aims which were:

1. to identify family needs for support during hospitalization and in preparation for a role as health care resource after discharge,
2. to explore methods for assessing family resources for managing the demands of hospitalization and home care.

The grounded theory which was constructed from the observational and interview data explained the family's integration of the illness and the events of surgery and hospitalization, moderated by strategies of containment. Containment was conceptually defined as the family's efforts, in concert with the changing conditions contexts to limit or regulate the disruption of the surgery and its associated implications for the family's pre-existing patterns of function.

In this conceptual framework, the family's adjustment, or management of illness and treatment and its implications for their lives over time was conceptualized as kinds of work. Three overlapping but analytically separate phases of the process of integration were identified: accommodation, confrontation and acknowledgement. The practical, or home work, the social, or relational and psychological work, the knowledge and health, or clinical work that families do varied over time and according to a number of factors and with different outcomes.

Accommodation

Before hospitalization, in managing the events of the development of the illness to the point at which treatment is sought and the patient is admitted to the hospital, the family was strikingly accommodative. Containment was evident in the family's elaborate compensation for the patient's increasing disability over time, the lack of confrontation or action on the part of the family in regard to the patient's developing illness until the patient was essentially housebound and in constant pain. Their health work consisted mainly of watching and waiting, allowing for the extra time needed by the disabled patient to carry out the activities of daily living. They did not seek information about the symptoms, relying on the patient for cues as to how much to participate and become involved. Psychological work of restraint and control, both to maintain the patient's autonomy and control and to reduce family disruption helps to explain the accommodation. Relational work to maintain the structural and emotional stability of family life, dictated knowledge and health work, keeping the family in a bystander role up until events immediately preceding and during the admission to the hospital. As the family was "called in" by the patient, they participated in decision making and evaluation of the data the patient was presented with in medical and surgical consultations preceding hospitalization.

There was variation in the nature and the amount of family participation at this time, by family relationship pattern and to the degree of alarm associated with the diagnosis or plan for treatment. Most families, however, remained poorly informed about the nature of the disease and its prognosis or the role of the family in its management at this time.

Confrontation

The phase of confrontation began for most families during the hospitalization when they were confronted with evidence of the seriousness of the surgery, and experience their own and the patient's distress associated with the surgery and the early post operative period. Some began this process at the time of certification, at the first surgical consultation when the patient was informed of a problem serious enough to warrant surgical intervention. The "surgical" or contained definition of the problem as a "blockage", or "blood flow" problem, rather than a manifestation of vascular disease, was still the dominant conception in most families' thinking until this time.

During hospitalization, the unfamiliar milieu and implied or explicit rules of the situation mitigated against the family's active participation or involvement, learning and integration. Once in the hospital the family had no direct jurisdiction over the patient's location, movement, activity, comfort, or fate. Their physical access to the patient was under clinical jurisdiction and not always clear.

Some families were more vigilant, less trusting than others, but all "contained" their concerns and restrained their activity and assertion of jurisdiction on behalf of the patient. Knowledge work was opportunistic and piecemeal. Families figured things out on their own, "configured", and stated that they didn't want to ask or didn't want to have to ask for direction and assistance.

Home work became an issue in the families' life at this time as routines and home maintenance were disrupted by trips to the hospital. Family earning work was not compromised, however. It was juggled with visiting schedules. Visiting was fit in around work schedules. The

family took on the added demands of being at the hospital by pushing other tasks and activities to other times, and doing more. For the retired or non-working family members, there was sense of purpose and fulfillment of responsibility or duty, a mostly positive interpretation of going to the hospital and staying with the patient. All families, even those with more emotionally distant relationships seemed to derive satisfaction from the hospital attendance.

Psychological work of performance control and identity management influenced the family's relational work with staff in the hospital. Families kept a low profile. They did not go where they were not invited, they did not make any "trouble" for the (as perceived) very busy staff or for the patient. Staff were also perceived as cool and uninviting, although a few families expressed appreciation for the thoughtfulness of particular nurses in the special care units and on the regular care floors.

Most care events occurred without notice to the family. Discharge from the hospital in many cases was precipitous; in most cases, coming days before the family or the patient expected it.

Families described strategies of managing the stress of hospitalization as praying a lot, keeping their cool, living day by day, limiting visitors, or (for a few) getting everybody involved, and knowing that that there was no choice and they were doing the right thing.

Discharge instruction was (perceived) as not having occurred at all, or as having been presented in general terms relating to the surgical recovery, rather than in sufficient detail or in relation to disease management. Families learned of discharge instructions from the

patient. One patient complained obliquely about insufficient discharge preparation before leaving the hospital. No families complained about not being instructed about recovery or illness care or requested additional guidance at the time of the discharge.

Thus, at the time of discharge, the family was a passive, uninformed participant in care, interested in doing their best, but without guidelines. Since they were not included, for the most part, in the events of hospitalization or the discharge instruction, they were left to their own devices to monitor recovery and manage the convalescence. Some knowledge of risk factors, particularly smoking, had by now filtered through to the patient's and the family's attention, but the information was generally in vague terms and still resisted by some. The implementation of any management activity or approach was left to the patient and family, who had their relationship as the major mediator of their interactions and health focused activity.

Acknowledgement

Acknowledgement, the developing realization of the realistic implications of the illness and the surgery for the life of the family, began with the first evidence of the disease for some families. By the third month after discharge, however, the cumulative result of the various conditions and family work over time was seen on the level, or state of the family's integration of the illness and the consequences of containment. Acknowledgement was also the result of confrontation with complications and disappointments over the illness trajectory to this point. During the last two months after discharge, acknowledgement is the major task for the family.

Two of the twenty-one patients at three months were engaged in a regular program of risk factor management by this time. One of the two had openly acknowledged the presence of vascular disease. The patients' families were interested and somewhat informed but not actively involved in risk management. Other patients' families had tried at first to join the patient in preventive efforts, (i.e., stopped smoking with the patient, cut down on fat content in meals, etc.) not in any systematic fashion, and once again without guidance or support from providers or other health care resources. Most family risk management was in desultory or non-existent.

Indications of beginning or partial acknowledgement of a disease process were evident in various statements and remarks about a new sense of vulnerability, or the wish that one had known to take better care of oneself. The "surgical" definition still persisted, or predominated, however. The few families who had evidently, by their statements, directly confronted the idea of disease had not confronted or undertaken an active role in its management.

At three months, some patients and families were angry; frustrated by their unmet expectations of a smooth recovery for a "blockage" repair, and their continued morbidity at three months. They felt betrayed and say they had learned not to trust doctors. Most patients (thirteen) rated themselves as 98-100% recovered, except for a few, "mostly irritating" remaining symptoms. About a third of the sample gave themselves lower ratings, from 50-85% recovered. They were still coping with pain and discomfort, lack of stamina and the return of high blood pressure.

All the surgeries were successful. One angioplasty done in conjunction with a renal artery reconstruction failed and had to be repeated. At the three month call it had just failed again, (or the surgery had failed, the patient was uncertain). One patient was concerned that the artery was blocked again, and the surgery "was for naught".

Throughout the trajectory, except for the family's home work, or practical tasks and activities of home life, and practical health tasks such as dressing changes, the family's health, knowledge, psychological and relational work each checked the development of the other. Containment strategies were employed to stave off the disruption of acknowledgement of the serious diagnosis and the intrusion of chronic illness into the life of the family. Without knowledge, families had to guess, "configure", watch and wait. "Configuring" and managing without help were a source of family pride.

The family relationships acted as a primary filter through which the family managed new information. In order to avoid conflict and family disruption and in an effort to maintain the agency, or independence of the patient, the family took no independent action in a health care role. They were not systematically included by health care providers in care decisions, activities or instruction. Without knowledge, guideposts, authority or enfranchisement of the family as a health care partner, psychological morbidity of depression, loss of trust, a sense of betrayal, emotional distancing and family conflict ensued and the family was not able to "muster" itself to deal positively with the illness.

The family's efforts to contain the crisis in the service of maintaining family stability seemed to have cost the family the opportunity to fully acknowledge the illness as a factor in their lives and to muster themselves for the work of containment in a positive, constructive sense: the "damage control", "limitation of spread" of the advance of the illness.

Most families in this study did not arrive at this positive and family-level acknowledgement of the nature of the illness, or muster themselves for the work of risk factor management over the time frame of the study, although a small minority had made more progress than the rest. What factors seemed to account for this finding, and the differences in these few families' outcomes?

Results of analyses of the family measures to assess change over time and difference between patient and family member's scores showed a significant rise in the patient's scores on the FIRM subscale measuring mastery and health from admission (time 1) to discharge (time 2). The family and patient scores on this scale were also significantly different at time 1. Family scores did not change and were at or above the standardized norm at both times. Patient's scores were well below the norm at time one, rising well above at time 2.

Family scores dropped significantly on the FCOPEs subscale "Mobilizing the Family to Seek and Accept Help" at time 2. On the measures of satisfaction with aspects of family life, the APGAR, patients had significantly higher scores than families at time 1. Scores were more aligned at time 2 (family scores up, patient scores down). Patients' scores were also significantly higher than families' at time 2 on the FCOPEs subscales "Acquiring Social Support" and

"Reframing." These data were conceptually compared to the qualitative data of the grounded theory. The generic measures' results corresponded to the theoretical framework and the framework provided substantive explanation for the findings of the instrumentation.

Empirical validation of the measures was accomplished by a case by case comparison of the family and patient scores with the observational and interview data for the same variables. The FIRM II did not seem to measure or capture a family effect of the illness before surgery, noted by the statistically significant discrepancy between the patient's and family's scores at time 1. Assessment of families at risk of deterioration or poor coping can be made on the basis of low and discrepant scores on the Family APGAR, which remained stable over time and corresponded to the qualitative data. The FCOPEs and the FIRM I were less discriminatory or consistently valid in comparison with the qualitative data of family function. The family and patient's definition of their situation was reflected in the scores on the FIRM.

Conclusions of the Grounded Theory

Conclusions drawn from the observation and interview data of the grounded theory must be approached with caution because of the small sample size. There was remarkable consistency, however, in the families' use of containment strategies and in its consequences.

Families did not "take hold" of the problem of peripheral vascular disease over the course of this study. Their mastery and morale depended on surrogate constructions, interpretations and solutions, which, perhaps, on some level were recognized as such as evidenced in

their lingering doubts and uncertainty. Some families came closer, made more of an effort, were better at confronting reality and gathering needed information, more energized and assertive. These were the partnerships. These families were affected, restrained by the same conditions however, which maintained their outcomes in a relative par with the others.

The data suggest that containment: controlling distress, damage to identity; "keeping the lid on", not reaching out of a limited, bounded area of knowing and acting maintains ambiguity and avoids or postpones despair but avoids, or short circuits, as well, the positive consequences of having integrated major life events and knowledge into the life stream in a constructive way.

On the basis of the data from this study, it is proposed that most families cannot accomplish the task of taking hold, or fully integrating the management of the disease into the family life without a great of (external) support or assistance. Families were not empowered, energized, or mobilized in an active care taking role by their interactions with care providers. They contained their responses, did not assert themselves or ask questions to both prevent disruption and to maintain self esteem and a sense of order, i.e., to behave properly in a situation. They remained as bystanders after discharge, taking major cues for action from their family relationships, in order to maintain family stability/avoid conflict and confrontation.

Families employed surrogate solutions to their lack of agency, or (situationally) enforced passivity. Religion was one of these: "Its in Gods hands". "God's been good to us". "I'll do my job, I'll pray." A "Turn Key" approach was another. In efforts to master the interface

with the professional medical community which was seen as overwhelming and inaccessible, to explain and to deal with ambiguity and uncertainty, they turned to what is understandable and known in their familiar realm of life, religion and obeying the rules of the situation. They "turned the patient over" to the care providers.

The hospital was not a resource for the family. Realistic conditions of hospitals today may not permit the kind of assistance that families require to effect change in life style and function or a positive construction of illness. Hospitalizations are too short, there are not enough staff, surgeons are (logically) focused on the lesion and the repair, and not the family's response.

The family seems to be, in general, a reluctant emotional care giver. They were better at concrete tasks of recovery care. Families seemed to take physical and practical nursing care tasks, such as sterile dressing changes, in their stride. For most of the families, however, a direct approach to the patient's feelings or experience was avoided. There was guarding against "babying", indulging the patient's illness, dependency or demands. It is as if the patient was a newly encountered person, with a new identity, and the relationship is unpracticed and unscripted. The family resisted the change of a new identity and relationship. When the patient role was resisted by the patient, there was less family distancing.

Recovery morbidities were largely unexpected and poorly understood, except for fatigue and pain of the first 72 hours after discharge. It was interesting to note that families seemed to take the patient's post operative hallucinations in their stride. In one case in which there was a great deal of distress in regard to the hallucinations, it seemed

that the family was not satisfied with the medical and pharmacological explanations provided.

Morbidity from the family perspective is more distressing than morbidity from the professional health care perspective, particularly, psychological morbidity. The treatment, with one exception, was successful. Claudication was alleviated. Patients were disabled and depressed, however, by unexpected extreme fatigue, weakness, pain, lymphoceles, infections, anorexia, swellings, bumps, sores, etc.

In the family's view and in this study's circumstances, the ambiguity and symptom-level management of the event appeared to be supported or, at least, not sufficiently interrupted by the professional care providers. The data suggest that containment may be a pattern of crisis management whereby the family system and the health care system interact to regulate the impact of a diagnosis or treatment on the patient and in the life of the family. In the context of an overburdened, tightly scheduled and financially monitored health care system, providers may feel that they cannot afford to "open the gates" of patient and family concerns. Describing distresses or complications that might be encountered may be considered wasted effort in an "effort-economical situation. An optimistic view may be considered wise and possibly as a preventive approach to patient care by some providers (i.e., not to "open the can of worms"). What resulted here in this study was that only a small minority of patients and families understood their illness or what they might be able to do to slow its progression or to reduce physical and psychological morbidity.

Conclusions of the Combined Analyses:

The Methodological Study Questions

This study's aims were both methodological and empirical, and focused on increasing nursing knowledge of the problems faced by families coping with major surgery and recovery in the context of a chronic disease as well as nursing assessment of families' capacity to manage a health care role.

The Identification of Families At Risk

The study asked whether families at increased risk of deteriorated family function or negative physical or psychological outcomes resulting from the crisis of major surgery could be determined on the basis of standardized measures of family coping and function. (Were the family measures valid indicators of these variables over time?)

To answer this, the triangulation of the observational data with the family measures' data was necessary. Change over time in family function and coping resources was assessed by the family measures and observations of family behavior in the situation and family interviews. Change was observed in a shift with satisfaction with family life, measured by the APGAR. The patients scores dropped slightly and the family scores rose at time 2. This study found that the highest and congruent APGAR scores predicted high and congruent scores at time 2, and low and discrepant scores at time 1 predicted low and discrepant scores at time 2. These scores corresponded to observations of family functioning and behavior and family interviews. The more isolated and higher conflict families had the lower scores. The "partnerships", or

more open, active and involved families had the higher and congruent scores. The other change over time in family function measured by the FIRM subscale II was not a family change. The change was in the patients' scores from time 1 to time 2, and attributed to the patient's ill health and definition of the illness. Change in coping strategies over time measured by the FCOPES was valid when compared to the observed family behaviors and reflective of the family's experience.

The survey analyses could assess family function at the two time intervals, but could not explain the findings. The patient's and family's understanding of their disease and situation and the social/environmental circumstances which influenced the family's behaviors and understanding in spite of high or low scores provided the substantive explanation. Further, the scores do not demonstrate the complex processes of family adaptation; e.g., the emotional and relational strength of a marriage in spite of poor or very censored communication, or the contributions of ethnic diversity to family problem solving.

The influence of the family's experience in the hospital on family function and capacity to manage a health care role, another study question, was assessed by change scores on family measures, field observation and family interviews. The significantly changed "mobilization to acquire and accept help" and "acquiring social support" FCOPES subscales scores combined with the the families' fragmented knowledge of illness and absence of risk factor management after discharge was explained in part by the observed lack of family participation or involvement during hospitalization.

The families' generally passive role was, in turn, a product of the circumscribed definition of the problem, the hospital culture, and the patient and operative procedure versus disease and family focused care.

Other influences on the family's contained response: avoidance of the distress of disruption, lack of knowledge, ethics of the larger culture, such as independence and the drive toward normalization, also documented in other family studies (Strauss, 1984, Krulik, 1980, Knafl & Deatrck, 1986) were evident in the interviews and observations.

Value of Proxy Family Measures

Instruments may help to discriminate between families who have and utilize more resources and those who do not; who have more conflict or discrepancy in their relationships or satisfaction with family life and partnership in problem solving and those who do not. In this study, the families with very high or very low scores at admission also had high and low scores at two weeks after discharge. Family functioning, measured by the instruments at the two extremes were not affected by the surgery and recovery.

An advantage of instruments is that they can precisely and efficiently assess particular aspects of coping, such as passive appraisal. They do not, however, provide substantive, contextual data with which to interpret the results. The definition of the situation and social interaction between the clinicians the patient and the family is the key to understanding family health care behavioral outcomes.

For example, passive appraisal is conceptualized as a coping resource on the FCOPEs. The circumstances and nature of the passive appraisal may also need assessment. Several patients and family members who had low scores on the Passive Appraisal subscale of the FCOPEs were among the best informed and involved family pairs in the study.

Contextual, qualitative methods and instruments are needed in family study for the valid interpretation of statistically generalizable

results. A "context laden", subjective-interpretive framework, based on study of the real, and not the hypothesized situation should accompany instrumentation in family study. Concurrent study of the context provides the strongest validation and explanation.

For nursing research, the utility of generic measures of family function may be questionable. Instruments which more precisely, directly address substantive issues and particular problems related to nursing assessment or interventions may have more application to practice. They may also more fairly judge, or accurately assess the impact of nursing care.

A study of nursing intervention provided during hospitalization to improve recovery following heart surgery, (Gortner et al, in press) found no apparent effect of the family nursing intervention on family measures at three and six months after surgery.

Perhaps the intervention was not of sufficient duration or intensity to produce the effect, as the authors note. Or, perhaps the family measures were not specific enough to the intervention.

Initially, this study was conceptualized in generic terms: the study of the effects of the crisis of major surgery on family adaptation. As the study proceeded, however, it became evident that the substance: the nature of the disease, the purpose and kind of intervention dictated the criteria for outcome evaluation. Mastery and morale were tied to the definition of the surgery and knowledge of the disease, the presence or absence of complications. The families' poor risk factor management was an outcome of the problem definition as well as family function processes.

Implications for Practice

The results of the analysis of the observation and interview data of the grounded theory have several implications for practice. Family participation and involvement in health care is best accomplished by invitation. Containment appeared to culturally and socially dictated in an uncertain situation in which authoritative jurisdiction is one sided, as well as a defensive maneuver on the part of the family to stave off disruption. It is therefore up to clinicians to initiate family involvement and to provide guidance and instruction as to the role, tasks and activities of the family for the care of an ill family member.

Family focused health care requires a systematic, multidisciplinary approach which accounts for individual differences in families and time for follow up. Further, family assistance should be targeted toward the patient and the care partner/s together to increase the likelihood of the family acting in concert; thus, health care information does not become a focus of family conflict with each person using the information to act out their individual needs and demands at one another's expense, or the expense of the patient.

Information about the disease and its seriousness and its prevention (or rehabilitation) should be "framed" in a positive, hopeful, manner, so that the family is recruited for the long haul of risk management. Realistic expectations of efforts (not miracles, but better health and perhaps a longer life) should also be set. Beavers (1986) stated: "Changing behavioral habits is as frightening to some people as losing a limb to arterial disease is to others." The difficulty of life style change and the stress of the family disruption

for risk factor management of peripheral vascular disease requires a program of systematic teaching and support, not "one shot" instruction.

In one text on the treatment of peripheral vascular disease, the author states: "When reviewing the results of reconstructive procedures for peripheral vascular disease, it is salutary to remember that from one half to one third of all patients undergoing femoral popliteal grafting for intermittent claudication will be dead in five years." (Savage, 1983, p. 23). One wonders if this estimate that is with or without a program of preventive/rehabilitative care. Most likely, it is without.

Studies are not yet available on the outcomes of risk factor management programs for peripheral vascular disease. One such program has been initiated at a local medical center by a cardiovascular clinical nurse specialist (personal communication with Cheryl Hubner, R.N., M.S. Coordinator, Vascular Rehabilitation Program, Alta Bates Hospital, Berkeley, California, 1988). This nurse began the program as an alternative to surgery, with health insurance reimbursement for the service. She now is accepting patients post operatively, and charging less, since insurance companies will not pay for the service. A self referred post operative patient who had been enrolled in the program for a year stated in an interview with this researcher: "They just gave up on me, sent me home to die. I read about this clinic and joined up. I never felt better."

Simple guidelines for managing emotional as well as physical recovery could be presented to families, although the function of the family's guarding, or trying to achieve a correct balance in their indulgence and sympathy for the patient and encouragement to "get going"

needs further study. Families were reluctant emotional care givers, distancing themselves from the patient's complaints, fearful of indulging or babying the patient during recovery.

It may be possible to accommodate the family's strategies of containment, to regulate the disruption by working slowly with the family over time, and providing a program of professional and non professional (such as other families coping with similar problems) support. (Or, as the research on hypertension has indicated, the family may need to endure an increase in stress before surgery while they are instructed about the disease and its consequences as well as the steps necessary for prevention).

The psychological morbidity associated with unexpected complications and uncertainty about recovery might be alleviated (or mitigated) by assisting patients and their families to anticipate the possibility of these occurrences and to understand the meaning of the symptoms. As the wife of one patient said:

They could have something in the system. For instance with my mother, a social worker said you can expect this and this. It could have been a nurse. You can say 'probably, or could be, although it differs'. It doesn't have to be a doctor, it could be a nurse.

(Guzetta (1984) has emphasized the critical importance of working closely with physicians in any health care instruction. The patient and family can be exposed to conflicting advice and become confused and distressed. Five of the seven participating surgeons in this study did not understand the need for family related research).

The data indicated that it is possible to recognize those families who are more open to active involvement in care and who may need less on going professional support. These were the families who could take on the work as a team as partnerships.

Families need professional support and guidance. All the families in the study needed more clinical support and guidance. None had fully acknowledged or integrated the disease's management into their lives by three months after discharge. Ethical consideration must also be given to the family's (informed) choice not to become involved in the health care of their relative, or the patient's desire not to involve his family.

An active, informed health care role for the family may require a substantial, coordinated effort on the part of the health care providers in various health care delivery situations and over time. Fragmentation of care associated with short, acute stressful hospitalizations may preclude the use of hospitalization to effect change in family health care behavior.

The hospitalization period may not be the optimum time for nursing intervention to modify family function or health care behavior. At best, hospitalization may provide a point of access to families at risk, a starting point, an introduction to concepts of disease management and family coping and a program of community follow up is necessary.

This study observed a lack of family involvement in the patient's health care relative to several conditions. One of these was a lack of invitation, or coordinated inclusion of the family in care during hospitalization. This suggests that, at least, the basis for family involvement and active participation, a kind of role indoctrination, could be established during hospitalization by inviting and including the family in care.

Resistance to family or individual change to undertake a program of risk factor management for peripheral vascular disease may be more

complex than is currently understood, especially if one considers the current daily publicity about health risk factors for arteriosclerotic disease. This problem needs further study, although the data suggest that peripheral vascular disease should be a cause for more alarm and family attention.

Implications for Family Study

Implications and recommendations for further research are based on the grounded theory and the results of the combined analyses of the family measures and the qualitative data.

The Grounded Theory

Implications for family study based on the grounded theory include:

1. the function of conditions such as symptomatology, disability, or the role of the family in furthering understanding which lead to the patient's decision to seek treatment in the context of developing disease.
2. conditions in the hospital setting which facilitate or inhibit family participation in care, including factors within the family, such as the nature of the patient-family relationship, family structure, and health history.
3. the effects of different structures of social support, community or professional, for family restructuring to manage health care for chronic disease should be examined.
4. ethnic differences on compliance with health care and morbidity.

5. the timing and the content of family focused intervention to manage peripheral vascular disease needs further research. These data suggest that the hospitalization may still be an opportune moment to begin to involve the family and introduce preventive care concepts and methods, in spite of the shortage of time or staff resources. The family is a "captive" population as they visit the patient in the hospital, and may be motivated by the experience of witnessing patient's distress at this time. A program could be introduced during hospitalization with systematic follow up by visit and by telephone and referral to support groups and outpatient services.
6. the function of the phenomenon of emotional distancing for families during recovery can be examined further to determine if this speeds or encourages recovery and at what cost, if any to the patient or the family.
7. the specific circumstances under in which approach and avoidance coping patterns are utilized bears further study. Research on approach-avoidance coping styles has direct relevance to family containment behavior. Coping styles can be considered as dynamic phenomena and subject to change as clinical approaches vary.
8. the morbidity created by fragmented care and the contributions of community based nursing care centers to reducing morbidity and health health care costs associated with this disease are other broad fields for research suggested by these data.

9. finally, further research is needed on the effects of risk factor management on morbidity and mortality for peripheral vascular disease. Specific areas of inquiry are the differential effects of various designs, timing and methods of programs to teach risk factor management, and the effects of family involvement on outcomes.

Recommendations for Combined Approaches in Family Nursing Research

Generic measures of family function and problem solving alone may not always be suitable for the study of nursing interventions. Assessment by these measures may be too gross to detect the effects of nursing interventions, such as family support groups and programs.

Grounded theory or other intensive field approaches should be considered as the basis for the development of family assessment inventories and these should be directed towards specific clinical problems or situations.

Family responses to the two methods used in this study did not indicate a preference for either one. Families generally tolerated the presence of an observer with little apparent self consciousness or distress, although dismay, distress and family conflict were more freely expressed in the individual interviews. Most of the patients and families completed the questionnaires, although the return at time 2, when families had to mail them back was 25% less than at time 1, when the researcher collected the questionnaires in the hospital. Questionnaires occasionally stimulated comments as explanation for responses. A few subjects wrote comments on the forms. Many had a problem defining who to consider as family when they answered the

questions, or how far back into the family history they should go to consider their response.

BIBLIOGRAPHY

- Anderson, J. (1981). The social construction of illness experience: Families with a chronically ill child. Journal of Advanced Nursing, 6, 427-434.
- Ball, D., McHenry, P., & Price-Bonham, S. (1983). Use of repeated measures designs in family research. Journal of Marriage and the Family, 45, 885-895.
- Barbarin, O., & Chesler, M. (1984). Coping as interpersonal strategy: Families with childhood cancer. Family Systems Medicine, 2, 279-289.
- Becker, H. (1978). Problems of inference and proof in participant observation. In N. Denzin (Ed.), Sociological methods (2nd ed.). Chicago: Aldine.
- Bloch, D. (1983). Family systems medicine: The field and the journal. Family Systems Medicine, 1, 3-11.
- Burr, W. (1982). Families under stress. In H. McCubbin, A. E. Cauble, & J. Patterson (Eds.), Family stress, coping and social support. Springfield, Illinois: Charles C. Thomas.
- Daley, L. (1984). The perceived immediate needs of families with relatives in the intensive care setting. Heart and Lung, 13, 231-237.
- Dhooper, S. (1983). Family coping with the crisis of heart attack. Social Work in Health Care, 9(1), 15-31.
- Doyle, J. (1984). The person with lower extremity arterial occlusive disease. In C. Guzzetta & B. Dossey, (Eds.), Cardiovascular Nursing: Body mind tapestry. New York: C.V. Mosby.

- Dracup, K., & Brey, C. (1978). Using nursing research findings to meet the needs of grieving spouses. Nursing Research, 21, 212-215.
- Ferraro, A., & Longo, D. (1985). Nursing care of the family with a chronically ill, hospitalized child: An alternative approach. Image, 17, 77-81.
- Fisher, L. (1982). Transactional theories but individual assessment: A frequent discrepancy in family research. Family Process, 21, 313-320.
- Fisher, L., Kokes, R., Ransom, D., Phillips, S., & Rudd, P. (1985). Alternative strategies for creating "relational" family data. Family Process, 24, 213-224.
- Gilliss, C. (1983). A comparison of patient and spouse stress associated with coronary artery bypass surgery. In M. V. Batey (Ed.), Communicating Nursing Research (Vol. 16, p. 33). Boulder, CO: The Western Interstate Commission for Higher Education in Nursing.
- Gonzales, S., & Reiss, D. (1980). The family and chronic illness: Technical difficulties in assessing adjustment. Paper presented at the National Council of Family Relations Annual Meeting, Milwaukee, Wisconsin.
- Gortner, S., Gilliss, C., Shinn, J., Sparacino, P., Rankin, S., Leavitt, M., Price, M., & Hudes, M. (in press). Improving recovery from cardiac surgery.
- Hampe, S. (1978). Needs of grieving spouse in a hospital setting. Nursing Research, 24, 133-120.
- Hansen, C. (1980). Living in with normal families. Family Process, 20, 53-75.

- Hill, R. (1965). Generic features of families under stress. In H. Parad (Ed.), Crisis intervention: Selected readings. New York: Family Service Association of America.
- Horowitz, M. (1986). Stress response syndromes (2nd ed.). Northvale, NJ: Jason Aronson.
- Janis, I. (1985). Coping patterns among patients with life threatening illness. Issues in Mental Health Nursing, 7, 461-476.
- Kantor, D., & Lehr, W. (1975). Inside the family: Toward a theory of family process. New York: Harper Colophon.
- Kazdin, A. (1982). Single case experimental designs in clinical research and practice. In A. E. Kazdin & A. H. Tuma (Eds.), Single case research designs: New directions for methodology of social and behavioral sciences. San Francisco: Jossey-Bass.
- Kestenbaum, V. (1982). The humanity of the ill. Knoxville, TN: University of Tennessee Press.
- Knafl, K. A., & Deatrlick, J. A. (1987). Conceptualizing family response to a child's chronic illness or disability. Family Relations, 36, 300-304.
- Knafl, K. (1985). How families manage a pediatric hospitalization. Western Journal of Nursing Research, 7, 151-176.
- Krulik, T. (1980). Successful normalizing tactics of parents of chronically ill children. Journal of Advanced Nursing, 5, 573-578.
- Kupst, M., Tylke, L., Thomas, L., Mudd, M., Richardson, C., & Schulman, J. (1983). Strategies of intervention with families of pediatric leukemia patients: A longitudinal perspective. Social Work in Health Care, 8(2), 31-47.

- Lazarus, R., & Folkman, S. (1984). Stress, appraisal and coping. New York: Springer.
- Leavitt, M. (1975). The discharge crisis: The experience of families of psychiatric patients. Nursing Research, 24, 33-40.
- Lewis, J., Beavers, W., Gossett, J., & Phillips, V. (1976). No single thread. New York: Brunner/Mazel.
- Lust, B. (1984). The patient in the ICU: A family experience. Critical Care Quarterly, 7, 49-57.
- Mailick, M. (1984). The short term treatment of depression of physically ill hospitalized patients. Social Work in Health Care, 9(3), 51-61.
- Mathis, M. (1984). Personal needs of family members of critically ill patients with and without brain injury. Journal of Neurosurgical Nursing, 16, 37-44.
- McCubbin, H., Nevin, R., Cauble, A., Larson, A., Comeau, J., & Patterson, J. (1982). The family coping with chronic illness: The case of cerebral palsy. In H. McCubbin & J. Patterson (Eds.), Family stress, coping and social support. Springfield, IL: Charles C. Thomas.
- McCubbin, H., & Patterson, J. (1982). Family adaptation to crisis. In H. McCubbin, A.E. Cauble & J. Patterson, (Eds.), Family stress, coping and social support. Springfield, IL: Charles C. Thomas
- McCubbin, H., & Patterson, J. (1981). Family stress theory: The ABCX and Double ABCX models. In H. McCubbin & J. Patterson (Eds.), Systematic assessment of family stress, resources and coping. St. Paul, MN: The Family Stress and Coping Project, University of Minnesota.

- McCubbin, H., Joy, C., Cauble, A., Comeau, J., Patterson, J., & Needle, R. (1980). Family stress and coping: A decade review. Journal of Marriage and the Family, 42, 855-871.
- McCubbin, H. (1979). Integrating coping behavior in family stress theory. Journal of Marriage and the Family, 41, 237-244.
- Miller, J. (1983). Coping with chronic illness: Overcoming powerlessness. Philadelphia: F. A. Davis.
- Mitchell, E. (1986). Multiple triangulation: A methodology for nursing science. Advances in Nursing Science, 8(2), 18-26.
- Molter, N. (1979). Needs of relatives of critically ill patients: A descriptive study. Heart and Lung, 8, 332-339.
- Moos, R., & Schaefer, J. (1984). The crisis of physical illness. In R. Moos (Ed.), Coping with physical illness 2: New perspectives. New York: Plenum Book Co.
- Norris, L., & Grove, S. (1986). Investigation of selected psychosocial needs of family members of critically ill adult patients. Heart and Lung, 15, 194-199.
- Oberst, M., & James, R. (1985). Going home: Patient and spouse adjustment following cancer surgery. Topics in Clinical Nursing, 7, 46-57.
- Pearlin, L., & Schooler, C. (1982). The structure of coping. In H. McCubbin, A. E. Cauble & J. Patterson (Eds.), Family stress, coping and social support. Springfield, IL: Charles C. Thomas.
- Pratt, L. (1976). Family structure and effective health behavior. Boston: Houghton-Mifflin.
- Rabin, C. (1981). The single case design in family therapy evaluation research. Family Process, 20, 351-366.

- Reiss, D., & Oliveri, M. (1980). Family paradigm and family coping: A proposal for linking the family's intrinsic adaptive capacities to its responses to stress. Family Relations, 29, 431-444.
- Ritzer, G. (1983). Sociological theory. New York: Alfred Knopf.
- Robinson, C., & Thorne, S. (1984). Strengthening family "interference". Journal of Advanced Nursing, 9, 597-602.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8(3), 27-37.
- Savage, P. (1983). Problems in peripheral vascular disease. Philadelphia: F.A. Davis.
- Schwenk, T., & Hughes, C. (1983). The family as patient in family medicine: Rhetoric or reality? Social Science in Medicine, 17, 1-16.
- Scott, D., Goode, W., & Arlin, Z. (1983). The psychodynamics of multiple remissions in a patient with acute non-lymphoblastic leukemia. Cancer Nursing, 6, 210-206.
- Silva, M. (1979). Effects of orientation information on spouses' anxiety and attitudes toward hospitalization and surgery. Research in Nursing and Health, 2, 127-136.
- Smilkstein, G., Ashworth, C., & Montano, D. (1982). Validity and reliability of the family APGAR as a test of family function. The Journal of Family Practice, 15, 303-311.
- Smilkstein, G. (1978). The family APGAR: A proposal for a family function test and its use by physicians. The Journal of Family Practice, 6, 1231-1239.
- Stillwell, S. (1984). Importance of visiting needs as perceived by the family members of patients in the intensive care unit. Heart and Lung, 13, 238-242.

- Storer, J., Frate, D., Johnson, S., & Greenberg, A. M. (1987). When the cure seems worse than the disease: Helping families adapt to hypertension treatment. Family Relations, 36, 311-315.
- Strauss, A. (1984). Chronic illness and the quality of life (2nd ed.). St. Louis: C. V. Mosby.
- Thorne, S. (1985). The family cancer experience. Cancer Nursing, 8, 285-291.
- Volicer, B. (1973). Perceived stress levels of events associated with the experience of hospitalization: Development and testing of a measurement tool. Nursing Research, 22(6), 491-497.
- Volicer, B. (1975). A hospital stress rating scale. Nursing Research, 24, 352-359.
- Volicer, B., & Burns, M. (1976). Preexisting correlates of hospital stress. Nursing Research, 26(6), 408-415.
- Volicer, B. (1977). Stress factors in the experience of hospitalization. In M. V. Batey (Ed.), Communicating nursing research (Vol. 8). Boulder, CO: Western Interstate Commission for Higher Education.
- Wagner, M. (1986). Pathology related to peripheral vascular disease. Nursing Clinics of North America, 21(2), 195-205.

APPENDIX A

Interview Guides for Data Collection

APPENDIX A

INTERVIEW GUIDES FOR DATA COLLECTION

Admission Interview Schedule

- I. Can you please tell me about how this illness developed?
- What did you first notice, when did you first know/discover the problem?
 - What action taken/steps/response?
 - How was the family involved along the way/give examples.
 - What was it like to live with this illness/these events/how has it/did it/affect the family life?
- II. What problems or difficulties have you encountered thus far?
- What would you say was difficult for the family during this illness? What about most recently?
 - How have you managed these?
 - What or who has been most helpful?
- III. What led to the decision to seek this treatment?
- How was the family involved in this decision?

IV. What would you say has been the family's general approach to managing during this illness? (How would you describe your family's approach, or way of dealing with this illness and treatment?)

- A family motto? Philosophy for managing these times? How does it relate to the past?

V. What about now--that you are here, in the hospital. How are you feeling now? How are things going for you?

- What is of greatest concern at this time?

- How are you going to manage the hospitalization? What arrangements/changes/accommodation in routine/normal life have been made/do you see will need to be made?

-Who/what will provide support for the patient and the family? What kind of support?

VI. What is your understanding of this treatment/surgery?

- What are your expectations?

VII. Do you have any special concerns, or any questions at this point?

GUIDELINES FOR THE HOSPITAL VISITS:

Ask for "chronicle" of events, i.e., what's happened since we last talked? (since we last met/last time I saw you).

Focus on coping strategies: (and what did you do; how did you decide to do that? how did you find out that . . . ?)

Check: Visiting patterns, schedules, interaction with staff, information gathering and sources, knowledge of care, patients condition, feelings, responses, participation in care ("hands on"?).

GUIDELINES FOR HOSPITAL DISCHARGE VISIT:

Determine patient's and family's level of knowledge of recovery course and recovery care, i.e., medications, care needs, risk factors, wound care, activity, etc.

Check notice given and family's accommodation to discharge.

Means of transport.

Observe processes--interaction with care givers, time frame, waiting.

Ask what is of greatest concern at this time for patient and for family.

GUIDELINES FOR 72 HOUR CALL

Ask how recovery is going? (chronicle of events)

How are you feeling?

Who is helping you?

Any problems, concerns?

Has anything surprised you?

Activity/energy/morale

Involvement of family in recovery

GUIDELINES FOR HOME VISIT:

Observe physical setting, and physical accommodation patient's recovery needs.

Chronicle of events, plus how family has managed events, problems, questions, decisions.

Current physical status.

Current mood/emotional status.

Morale.

Improvement vs. expectations of improvement.

Activity level and type/pattern.

Determine mastery: sense of competency, success vs. vulnerability, defeat, failure, uncertainty--individual and patient.

I ask: "Looking back at this whole experience before the surgery, as the symptoms of the illness increased, during hospitalization and now, during recovery--what are you especially proud of, or feel good about, about how you have managed"?

"What, if anything, have you learned from the whole experience"?

APPENDIX B**Analysis Worksheet Sample**

Worksheet: Validity Assessment/Analysis

Observation Code:

#	Patient		Family	
	T 1	T 2	T 1	T 2
APGAR				
FIRM				
I Est & Comm				
II Mast Health				
VI Soc Des				
F-COPES				
FCASS				
Acq Soc Supp				
FCREF				
Reframing				
FCSSS				
Seek Spir Supp				
FCMF				
Mob Fam Acq/ACP				
Help				
FCPA				
Pass Appt				

APPENDIX C
Case Histories

APPENDIX C
CASE HISTORIES

Illustrative Case History #1

Introduction

E.S., a sixty-six year old, single woman of Irish descent was admitted to the hospital for a femoral popliteal bypass graft. Symptoms leading to this surgery were intermittent claudication for the last two years, and a "heavy thigh" in her left leg, becoming more severe and, finally, incapacitating in the last few months. The patient stated that a neighbor recommended that she consult with a physician, who found no pulse in her foot. She stated: "I might blow it out, but it was getting worse. I was a little concerned. I need to walk. I do things by walking."

The patients "clinical" family (the members most involved and responsible during the surgery and recovery) consisted of her older sister and brother-in-law. The patient described her family as: "My sisters, their husbands, my nieces and nephews." The patient lived alone in her own apartment, a third floor walk-up. Her younger sister was departing for a European trip the day of the patient's admission to the hospital.

In response to explanation of study's family-centered aims, the patient remarked: "It's a good idea. Families just don't know, don't really know what it's like. They don't bother."

Health History and Definition of Current Problem

The patient described a health history of many surgeries for unrelated problems since childhood, and severe arthritis. A diagnosis

related to this current surgery was not mentioned in the initial interview before surgery, although the patient asked the researcher several questions such as:

My hands and feet hurt with the arthritis. Now my arm hurts. I wonder, is it another blocked artery? How do they do this operation? Do they put a tube in? How long is the recovery? Can I walk when I get home? Will I be sick after surgery? I'm afraid of getting the heaves, sometimes I get them so bad my stitches break.

She was advised that these were all important questions and that she should ask her physician about them.

Regarding recovery care, the patient said:

I want to be at home. Do you think I should go to my sister's or to my place? They offered to take me home. [What are your thoughts about it?] I like my place very much. It's better for recovery. You have to do for yourself, can do what you want, you don't depend on other people. Friends will come by. I have a third floor walk-up, though.

The researcher called the patient's sister to describe the study and to ask for her participation. The sister consented, adding: "I'm glad you have talked with her. She is a very nervous person, extremely nervous. She was having a terrible time walking."

Surgery and Hospitalization

The surgery went as expected; there were no complications. The family came to the hospital at 6:45 A.M. on the day of surgery and talked with the patient and remarked that she was "relaxed and not like other times," which they attributed to her participation in the study. They waited in the hospital lobby during the surgery. They told the researcher they "didn't mind" taking care of her and coming to the hospital. Since they were retired and had the time, "this is something we have time to do, we can do this, we want to, to be here to help her."

They also said they hoped things would go well, so they could take off to a family reunion scheduled for the next week.

They were called to the lobby information desk at 10:45 A.M., an hour past the time estimate they were given, to speak with the surgeon, who said everything went well. The hospital stay was without incident. The patient made a rapid recovery and seemed in good spirits. The family visited occasionally and the patient received telephone calls, flowers, and cards from friends and other family members.

The patient asked the investigator again, in subsequent interview during the hospitalization, what caused this blockage. When asked: "What do you know about it?" the patient responded, "I think it's from my parathyroid problem. It caused my kidney stones, or maybe from my foot operation."

The family was "amazed" at her recovery: "It seems faster than we thought" and were anticipating the patient's reaction to recovery before the discharge.

We wonder about her walking. Is she going to hold back too much? She has a tendency to baby herself, to have others do things for her. We won't let her. It's not good for her recovery. [Where did you get this idea?] You just get stronger if you are more independent. We read and watch T.V. programs and we have our own experience. When K. had her last baby they got her going right away and that was much better for her.

The patient's discharge came earlier than expected, six days after surgery. Her sister was out of town. The patient called her niece, who could not pick her up because her daughter had an appointment with the school psychologist and she had to be there. Her niece called the sister, as did the patient. The sister said she would leave her vacation home earlier and be there by noon the next day. On the day of discharge everyone was pleased with patient's condition and result. The

patient said she would take them out to lunch. On the 72 hour phone call the sister said everything was going well; they had been out walking.

On the home visit to the sister's home (earlier than the research protocol because patient's planned stay with family was only five days), everyone was pleased with the patient's recovery progress. "Her walking is 100% better. She could only shuffle before." Some family tension was noted, however. The patient complained of the shower being too small, the house too cold. There was a small, reddened, and opened (fresh scab) area on her incision. Her brother-in-law's response to the investigator's questions about this was: "Now look, you've made a thing out of it, now we're in for it. She'll worry now." The sister said: "I saw it but I didn't say anything, I didn't want her to get worried." The patient said she didn't say anything because she was waiting for researcher to see it. She was advised to shower and rinse with warm water and watch for signs of worsening, and call doctor if it worsened.

The patient had shopped and made dinner for her sister and brother-in-law the evening before. She wondered if she had been too eager and done things too quickly because she was "really tired."

The patient returned to own apartment as scheduled, five days after discharge. She developed pneumonia soon afterward, which she attributed to being too cold at her sister's house. She also complained of having trouble sleeping. The sister and brother-in-law were out of town.

Home Visit to Patient

At the time of the home visit, two weeks after discharge, the patient had a low-grade fever, looked pale and ill. She was taking an

antibiotic prescribed by her physician and complained of having no strength, and feeling "a little down," which she attributed to "so much excitement recently; so many people around and now there's nobody." During the home visit, the patient reviewed events before the surgery, saying: "The doctor wanted me to go right to the hospital from the arteriogram. I said no. I wanted to be ready. That was good; I was." She also remarked that

. . . I'm still puzzled about how or why this has happened. [What have you been told?] The doctor said it was a clogged artery. The radiologist said it was hardening of the arteries. Dr. ___ agreed with him. I still think it was caused by my parathyroids, the calcium and all.

The patient said she felt let down by her family. When asked, "Do you feel you got the support you needed from your family?" she replied, "Not really. At first they were there, then not so much. R. began to make snide remarks about using up too much gas to take me to Doctor's office. I was hurt. We were never that close anyway."

During the visit, a neighbor stopped by to check on her and said she thought she (the patient) did not look so good. She seemed bereft, sick, and lonely.

At one month after discharge, the patient reported that she had suffered a collapsed lung, a result of the pneumonia and walking uphill, but that all problems were now resolved. She had some soreness in her leg that had frightened her. She had seen the surgeon, who said it was healing fine and she felt reassured. At that time she remarked that the doctor asked her when he could operate on her other leg. She said she told him to get lost.

She has been getting out to the store and to visit friends, although she was still mostly confined to the house and feeling weak.

She had not seen her sister or brother-in-law. She repeated that she thought she got the pneumonia at her sister's house while there because

. . . they didn't put the heat on. They had no consideration; I was glad to get away from there. I would never go back. There was a discussion of money, you know. Should I pay them for taking care of me. I offered a check of \$100.00. They wouldn't take it. I made dinner for them. R. said he'd rather have money. I gave them a check for \$20.00. They expected more. I paid them the last time, too. [Perhaps we were wrong to encourage you to stay with your family after discharge.] You are not doing good to push that. I was unhappy and not relaxed. I would have rather be at home. It's touchy. I'd be more comfortable with perfect strangers.

She asked once again:

Do you think my foot surgery made this worse? [Have you asked the doctor?] No, and how come it's only one leg? I never had a cholesterol problem, always under 300, only once, a year ago it was a little high. My mother had hardening of the arteries. [Diet and heredity play a part.]

In a separate telephone interview with the patient's sister, at one month after discharge, she said she thought things were "going very good" although she (the patient) had pneumonia. They had not seen each other since the patient moved home. "We are always on the go. I talk with her on the telephone. She complains a lot. I never ask her how she feels, afraid it will start her thinking."

She asked how the study was going, and explained: "I don't think the forms we filled out apply to us and E. We don't live with her and she's not such a big part of our lives."

At three months after discharge, the patient reported that she was feeling fine except for an arthritic, "frozen" shoulder. She said: "The operation was `real good.` "Life is back to normal. I went out to lunch with a girl friend, out to a party." In response to a question about how things were with the family, the patient said: "No change there, with family, we keep in touch."

The sister reported that the leg was marvelous although she had other problems with her arm. She (the patient) was going to physical therapy, however, and getting better. "She's been on her own, we haven't seen much of her. We keep in touch."

This is a case in which the family's normal relationships were disturbed by the health crisis. The family was forced into a different relationship, one that required closer, more intense contact and the patient and the sister and brother-in-law were on guard about the change. Initially the family seemed responsive and concerned. They then began to demonstrate increased resentment of their obligation and added tasks. In fact, they were "on guard" against added demands even before the patient's discharge. At two weeks after discharge the patient was sick and depressed. This case illustrates well the phenomenon of anticipatory family "guarding" against sick role behavior and that, although the family may feel responsible and willing to take on the tasks of (at least early) recovery assistance, they may not be emotionally equipped to do so. The patient was bitter and disappointed and a little angry at herself and the care providers for not being more assertive about going to her own home.

This case also illustrates the patient's efforts to define and understand the disease or problem leading to the need for surgery. The patient's questions, repeated over time, along with attempt to test her own explanations of the illness, suggest that a disease definition of the arterial blockage was not incorporated and, perhaps, resisted. The operation was a success, but many doubts and important questions and concerns remained long after the surgery.

Illustrative Case History #2

Introduction

The patient, a 57-year-old married man, was a self-employed, financial planner who was admitted to the hospital for a femoral popliteal bypass graft for a right popliteal thrombosed aneurysm.

History and Development of the Illness

The patient had a long history of high blood pressure and heavy smoking, and a (relatively) short, six-month history of progressive claudication, stable until three weeks before his hospital admission when he awoke with a "blanched" foot. He sought treatment first from an orthopedic surgeon.

The "episode" (his wife's word) started six months prior to admission. "We first went to an orthopedic surgeon, who gave him two cortisone injections in his spine, and then he woke up with a white foot and blue toes." The pain had been "on and off" for some time, always relieved by rest and was not a cause of alarm until that time. They then consulted a vascular specialist, who did angiography and sent them to the vascular surgeon. "We came in for the surgery as soon as it could be scheduled. We wanted this taken care of," his wife said. This couple was technically well-informed about the aneurysm and the graft procedure.

Family

The patient's wife was the sole care partner, although they had two grown children who lived in the same geographical area with their own

families. This couple spoke of situations and problems in terms of "we", as a team.

The couple resided 60 miles from the hospital. He was open and brusque, concerned about his wife and her need to travel to and from the hospital daily. "She relies on me." Both smoked. The patient would "definitely" be quitting with this surgery, the wife said. As an example of their partnership, or team-like approach, they strategically arranged for a joint orientation to the surgery on the evening of admission. The patient asked the surgeon to wait for his wife, who was on her way to the hospital, to discuss the surgery. "He waited for me. I was so glad he did."

The surgery went as expected. The patient stayed overnight in the special care unit, although he did not see why that was necessary. "The minute I knew where I was I told everybody to get me out. I nudged them, the doctor, too." His post operative course went smoothly. His wife said she felt "fine, now that the surgery was over." By the fourth post operative day they were both pleased with his progress. His wife said "he looks great. He showed me his incision last night."

Although this couple made accurate statements about the aneurysm being caused by smoking and high blood pressure, they did not discuss the prognosis of the disease, or the diagnosis, in terms of (systemic) arterial disease. The wife asked: "His blood pressure is under good control with medication. Why there, though, in that spot and why now? He was told he had such good circulation and great arteries."

On the morning of discharge, she was asked if she had any concerns or questions. She said "No, R. got all the information he needed. Dr. G. has been great. I don't know what I would have done if I had missed

that meeting on the first day. It might have been just a lucky accident, but it sure helped me. I'm the kind of person who likes to know, good or bad. So I can cope with it. R. too." She looked at her husband's yellow note pad, and said. "It says visit with M.D. for staples out next week, golf in two weeks, driving in three weeks." No one had spoken with her about recovery, however. She knew about the vascular booklet, had looked it over. The researcher mentioned the need for a low fat, high protein diet. She said: "That means no bacon. I need that written out so he'll pay attention. He won't if I just say so."

By the 72 hour follow up telephone call after discharge, they had called the surgeon because they became concerned about the patient's "very swollen foot." At that time, they were advised that the patient should lie down or walk around; "no sitting." The wife remarked: "It was swollen by the time he got home. They kept him sitting the whole time he waited for the ultra sound--that probably made him swell."

On the call to arrange a home visit, the patient said he "was going crazy with not smoking," and with not being independent: "I gotta wait for somebody to drive me all the time." On the home visit, the patient's physical status was such that he still could not wear shoes. His right leg and foot were still quite swollen. He complained of lack of sensation on top of his ankle, "anterior tibial nerve damage" he said. He had received an estimate of the resolution of these two problems as "2-3 months." He had returned to work and was not engaging in regular exercise, or any dietary changes for risk factors.

They reviewed the problem with leg swelling. The reason for the swelling was attributed to having to sit and wait for his "last minute

ultra sound." The patient stated that the doctor had said, "Don't just stand, walk; recline, don't sit. They could have said that before I left." He wife asked: "He didn't say how long he had to lie down--another week?"

They also reviewed events leading to and during hospitalization. The patient said: "It was a shock to find the aneurysm. Nobody had mentioned that, a big surprise, and I didn't think it was going to be as big a deal. It wasn't until the hospital that it was totally clear. That first talk was beautiful. He did a hell of a job." The worst time for the patient's wife, she said, was "being in there when surgery was being done, not knowing what was happening, worrying." For the patient, it was "the first night after the surgery, in the C.V.S. I hated being around all those sick people."

They reviewed their strategy for managing. "We worked as a team, took it one step at a time. We both understood what we want, no visitors, no flowers. We learned from past experience that when somebody's sick it's not the time to visit."

The biggest problem from the wife's point of view was the distance from the hospital to home: "I was anxious. It (the hospital) was a foreign territory. You don't want to ask questions. I learned that I am too dependent on him."

They identified their philosophy for managing. The patient said, "Don't take yourself so seriously, calm down." They had advice for other couples. The wife suggested: "Drive people crazy asking questions. Don't feel stupid. Know what's going on. If you know, you can handle it. Something was wrong. We wanted it fixed."

At one month, the patient said: "It's over, I'm 100%. I can wear regular shoes, that meant a lot. The worst is over. Everything is back to normal, except the swelling is not completely gone." Asked if he was exercising, he replied, "I walk every day, it varies how far and how long." About smoking, he said "I quit, then had a couple." "We're going golfing in Carmel next week, I'm seeing the doctor for a check up today. Oops, I've almost forgotten his name!"

At three months, the patient reported that things had gone "without a hitch," although the foot and ankle swelling was still present. He said: "A permanently larger foot, I guess." Asked if the physician had seen it, he replied: "The last time I saw him I was swelling daily." He also remarked that "it is annoying to feel the leathery skin in back of the knee, but I'm able to do everything I want to do."

Asked about smoking, exercise and diet, he replied: "I'm not walking as much as I should. I'm still smoking, but 50% of former consumption though." [Diet?] "You mean low fat? Reasonably, but not a strict diet--no butter, but red meat now and then."

Asked for a final evaluation of the whole experience of surgery, the patient remarked: "I've more or less forgotten the whole thing, except for the swelling and numbness. I was back to work five weeks after surgery. Our lives were not really normal, though, until I could wear regular shoes."

This couple's case history illustrates several comparative factors and dimensions in the theoretical analysis. First, the development of the early symptoms was not responded to. These only figured retrospectively in their conceptualizations of the illness. Only the dramatic symptoms of acute arterial occlusion, the "blanched foot," demanded their attention, concern, and a search for immediate treatment.

Even with their active and rapid search, however, the problem was initially misdiagnosed and mistreated, contributing to a lack of clarity about the illness.

In the hospital, they worked as a team. They planned their approach (as much as possible) and strategically arranged to be treated as a team in initial conferences with the attending physician, who was asked to wait for the wife's arrival at the hospital and who was able to accommodate that request. This couple's interactions were generally open and relaxed.

Even this open partnership couple did not directly confront the illness or ask vital questions about the patient's health or health care. They harbored questions, like the wife's about the aneurysm, "Why there and why now?" and did not directly express their irritation with lack of anticipatory care information about the patient's foot and leg swelling.

Their knowledge of risk factors and disease management was vague and superficial. He did not quit smoking, was not exercising, and had made only slight dietary changes. This was a patient with chronic hypertension and vascular disease. Neither the patient nor his wife demonstrated knowledge about the nature of his disease or its preventive management.

Three months after discharge, the patient was proud of the fact that he had "forgotten" about the whole thing and that life was back to normal. In spite of their good working relationship, their active problem solving before admission and during hospitalization, they had not integrated the fact that they were living with a chronic, progressive disease whose progress could be stemmed or slowed by risk factor management.

APPENDIX D

Recovery Morbidity by Stages

APPENDIX D

RECOVERY MORBIDITY BY STAGES

D-1. A Summary of Morbidity at Two Weeks after Discharge by Procedure

AFBG patients (11): general complaints: (unexpected) fatigue, lack of energy, weakness. Individual complaints: leg cramping, incisional pain (1); incisional pain with movement, raw, sore throat (1); incision extremely sensitive to touch (1); lower abdominal pain (1); bilateral ankle edema 3+, hospitalized for chest pain (1); incision not healing, opened in abdomen, groin area, leaking serous fluid (1); hard, inflamed swelling on groin incision, fever (1); discolored and painful great and second toes (1).

AAA patients (3): generalized weakness and fatigue. Specific complaints included: acute gastrointestinal distress, unable to eat, aching testicles, pulling, painful stitches (1).

Femoral popliteal bypass and femoral artery reconstruction patients (5): Opened incisions (2); bleeding on groin incision (1); leaking lymphatic fluid at groin incision (1); pneumonia, (1); leg, ankle and foot swelling (2); aching behind knee (1).

Subclavian aneurysm (1): extreme incisional pain, fatigue and weakness.

Renal artery reconstruction (1): incisional pain, swelling on right side, fatigue and weakness.

Of the eleven patients who had undergone aortofemoral bypass grafting, none had as yet returned to previous normal activity levels, although two had returned to work part-time (a few hours a day). Most were still convalescent, not dressed, and staying in the house. Two had made early, vigorous attempts to exercise, but both had stopped, because of pain or complications by two weeks.

The other patients had similar limitations at two weeks after discharge. No one had returned to work or to previous normal activity levels by this time. One had made an early and overly vigorous attempt to exercise and had stopped because of acute discomfort. All expressed dismay at not making more rapid progress, not "bouncing back." Those with complications, such as lymphatic drainage, were angry and distressed. Those with swollen feet and ankles and sore toes could not get out, except for visits to the doctor's office, because they could not wear shoes.

In summary, early (the first two weeks after discharge) family struggles were with emotional and physical sequelae of continued fatigue, weakness and recovery complications. Families responded to the patients complaints by emotional distancing and limit setting, as well as concern and uncertainty. The patient's sense of betrayal by unexpected and underplayed morbidity and complications was shared by families who had closer emotional ties and a team-like relationship. These families reacted with anger and pulled together to get proper attention.

D-2. A Summary Analysis of Risk Factor Management at Three Months

1. Smoking. Six were still smoking, although three said they were smoking 1/2 or 3/4 as much as before. Four had stopped smoking as a result of this surgery.
2. Diet. Two were following a low fat diet regularly. (One of these was well informed about her disease.) The others displayed a range of awareness of the need to monitor fat intake from slight, "lip service" awareness, i.e.: "Not on a strict diet, eating less meat." "I use less fat to cook," "I squeezed the fat out of the hamburger when I was frying it," to moderate awareness with little dietary change: "We're watching it, but we slipped over the holidays." After describing a breakfast of bacon, eggs, and peanut butter on her toast, she said: "We only use unsaturated fat when we fry." "Using corn oil margarine now."
3. Exercise. Six patients were now engaged in regular, planned exercise; four in the context of awareness of disease, (risk factor management), two as rehabilitation/recovery work. Seven were exercising irregularly, aware of the need to do so, as disease management or as rehabilitation/recovery from surgery: "I walk, I walk to the grocery store, walk most places, I did that before." "I'm walking all over the hospital as part of my volunteer work, walk the stairs instead of the elevator." "I'm playing tennis." "Nothing regular, playing golf." Eight were not exercising at all, but for different reasons. Six of these did not feel physically able, were still weak or had complications or new physical problems, such as lung cancer surgery, and two did not and did not plan to, and were aware of their disease.

FOR REFERENCE

NOT TO BE TAKEN FROM THE ROOM



CAT. NO. 23 012

PRINTED
IN
U.S.A.

