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FAMILIES IN CRISIS: PATTERNS OF COPING WITH SERIOUS ILLNESS

by

EDWARD J. SPEEDLING

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Abstract

FAMILIES IN CRISIS: PATTERNS OF COPING WITH SERIOUS ILLNESS

by

Edward J. Speedling

Adviser: Professor Emily Mumford

This study reports on the experiences of eight families following a heart attack to the husband-fathers. Through interviews and participant observation in the homes, which began soon after hospitalization and lasted over five months, patterns of coping with the crisis were identified. The findings indicate that during hospitalization patients and members of their families develop discrepant perspectives on the illness and the recovery process which results from their different access to the setting of care. These dissimilar definitions of the situation have an impact on the family adjustment when the patients return home. After hospital discharge, coping patterns are seen to follow from basic structural and cultural components of each family. Among the families, differences in coping were associated with variations in division of labor and companionship. Families in which the members preferred a role-exchange type of division of labor inclined toward early withdrawal from illness related roles and a return to pre-illness relationships. In contrast, where role differentiation was valued in the family, patient-husbands remained in the sick role and their wives in nurse-surrogate roles for a longer period. Secondary gain from illness is offered as a partial explanation for this difference in response. Sources of conflict differed among the types of families. In role-exchange families, conflict was associated with the necessity for members to remain in illness-related roles; in families where role differentiation was valued, conflict was most serious when husbands felt ready to leave the sick role.

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Finally, my wife Eileen provided me with a constant source of support and encouragement, and was ever open to discuss, critique and appraise this work. Her companionship was vital to my ability to sustain the effort required to complete this work.

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Chapter 1

Introduction

This is a study of family in crisis. It aims to identify the problems which are likely to beset any family following a life threatening illness. Drawing on data gathered from interviewing family members and health care personnel, and from directly observing families at home and in the hospital, the analysis shows how eight families tried to cope with the illness - in its acute, critical phase, and later during the home-based rehabilitation.

Identifying stages of response to crisis was a primary aim of the study design and is one of the major findings of this work. This refers to the sequence of problems any family might face as the crisis unfolds. In analyzing the response to crisis through time one looks for turning points which mark the transition from one stage to another and the "critical events" which cause behavior to follow one path rather than another.[1] This progression through stages can be conceptualized as a "moral career" of a family in crisis.[2] As such, it refers to the social context of the crisis: the definitions of the situation, and the normative expectations for behavior in the crisis situation which prevail in the social system for its members. Interwoven into the fabric of family response at each stage of illness are perceptions gleaned from the external social world which simultaneously are given specific interpretation within the individual family culture.

A significant part of the social context for the family coping with serious illness will be seen to be medical professionals. In their role as definers and healers of illness, physicians and other members of the health establishment provide laymen with ways of thinking about the illness, and of playing roles of patient and family-of-patient. In families where treatment of the condition continues at home, members' participation in the medical regimen can have significant consequence for a wide range of family activities. One question for analysis concerns how the requirements of the medical regimen can be made compatible with the family's value system and social structure? More specifically, what is the role of the family in the management of an illness which, while sudden and acute in onset, has long term consequences such that serious alterations in the social life of the patient are called for? A factor which must be taken into account is the special nature of the health care system charged with the care of these patients. The health system under scrutiny here is a prepaid group practice (called Medical Group in this document), which, in its organizational structure, departs in several important ways from the more common fee-for-service arrangement. Our study will examine the relationship between the family and the prepaid group practice (Medical Group).

In order to address questions like these in this study, I analyze interaction between family members and the health professionals who cared for the patients. Included are observations I made of such interaction when it took place in the hospital. Data will be presented on how personal experience in the medical setting influenced the manner in which family members perceived the illness and its future consequences; what they understood the medical regimen to be both in the hospital and at home; what each felt his role was to be throughout the illness and especially during home care. During hospitalization the opportunity to interact directly with medical staff, and to observe them at work, is not the same for the patient who is "full time" as it is for his kin who visit him. This raises an additional question: To what extent are definitions of the situation shared among patient, family, and medical staff?

This study of families in crisis provides an occasion for addressing important questions in the sociology of marriage and family relations, especially those concerning stability and change. Hansen and Hill comment on the theoretical significance of family-in-crisis research. "Sociological research on families under stress offers the most systematic investigation of the rearrangement of roles and other aspects of family organization that enable a family to cope with crisis and survive."[3]

A crisis typically creates a situation which alters normal family routines and patterns of interaction. It renders problematic many taken for granted aspects of group life. What are the attributes of families which manage to alter routine patterns without disorganization? And of those for which the crisis threatens dissolution? What can account for differences in the way families attempt to solve the problems brought on by the illness? What can account for the variations in outcome of the crisis period for group stability and integrations?

Literature Related to the Study Questions

As reported in the medical and social science literature, the experience of families in the crisis of serious illness is often associated with a number of unfortunate sequelae. Studies have found that marital discord, including divorce, often follows illness.[4] The emotional health of children has been reported to be adversely affected.[5] Illness affects the entire family.[6-7] Relationships between even the non-ill members are placed under strain.[8] Studies focusing specifically on heart disease suggest similar problems. In their study of 54 families of heart patients, Jacobson and Eichorn describe a variety of coping problems. One is particularly revealing: "There were so many constraints on free communication of fears, hopes, and affection within some families that every family member was, in a real sense, isolated."[9]

Other researchers of heart attack victims and their families have, consistently, corroborated this gloomy observation. Dobson and his associates,[10] for example, have reported that 40% of their sample experienced serious marital problems after hospitalization. Honeyman's research found that "through a process of identification, children of heart disease parents acquire a propensity for verbalizing hypochondriacal concerns and a rather depressed outlook."[11]

With the increasing prevalence of chronic illness in society, more families than ever before are certain to contain at least one member whose functioning is limited by physical incapacitation.[12] At the present time, however, changes in medical care planning are encouraging early hospital discharge of patients whose care will be continued at home, using family members to carry out the treatment regimen with the support of portable technology and periodic visits from medical personnel. These trends give a measure of practical necessity to studies of the social processes of coping with serious, chronic illness, if only to find ways of relieving the heavy burden of illness on the family.

The research findings appear to illustrate the analysis made by Parsons and Fox[13] of the reasons for the unique unsuitability of the family as a site of care for the seriously ill. The modern nuclear family, they argue, is already burdened to its limit of tolerance in its role as society's "shock absorber":

absorbing and dealing with the consequences of the strains members encounter in their experiences in the impersonal marketplace. When one member draws on the care-resources of the family, if the situation continues too long, the other members are deprived of much needed support and services. With its typically small size and sharp diversions of role function, the withdrawal of one person from normal role playing, even because of an illness that is beyond his/her control, is a serious problem indeed.

In the view of Parsons and Fox, illness management in the home is especially threatening to family relationships, which because of their high emotional content are vulnerable to strain even under normal circumstances. The relationship between a patient and the persons caring for him departs from the normal pattern among adults in family life. In its dependence and in its freedom from normal reponsibilities, the patient role is a privileged one, and has some attributes of the child role. In a society as demanding as ours, this privileged position might be sought as a welcome substitute for normally stressful role obligations. Ideally, the role of healer in society deals with this contingency. First by encouraging the patient to suspend his attachment to adult concerns, he elicits the patient's trust. Then, as the treatment takes effect, he withdraws support for dependency and offers approval for a return to normal role responsibilities.

Where family members are asked to share in the therapeutic process by taking over the therapist's role obligations, their emotional connections to the patient make it specially difficult to maintain the required objectivity and affective neutrality. More often, the tendency on the part of the family members is to overindulge the patient, thus inviting him to perpetuate his illness; or, to be overly strict, and intolerant of the patient's dependency. In either case, the tensions introduced by the illness will be compounded.

Others working in the field of crisis and the family offer a different interpretation. Concerning the question of the medical consequences of home care, Gersten, Miller, et al. compared matched groups of chronically ill persons in home and hospital-based care programs. They report: "In both home and clinic groups there was significant improvement in functional status and life pattern, with a tendency for life-pattern improvement *to be greater in the home group*"[14] (emphasis supplied). There was no significant difference between the two groups in their degree of improvement in the different care settings. This would seem to suggest that with adequate support from the medical care system families can contribute positively to the care of the patient-member. One must be cautious in interpreting these results, however. Programs like that reported on by Gersten, Miller, et al. are, by and large, demonstration projects. Enthusiastic participation of program personnel to the new concept of health care delivery might not be sustained over time, or be matched when such programs become more routine. Furthermore, the families selected for such organized home care programs may not be similar to the bulk of families who have to cope with lengthy home based recuperation, often with less help from their health care system.

Additional arguments for the point of view that illness need not always be a severe burden on the family's ability to function are made by Hansen and Hill who claim that family disorganization following illness of a member has been over-reported. Over-extension of the "system" metaphor and the assumption that homeostasis is an essential ingredient of the family system has, they suggest, led to "bias toward static, reactive behavior under stress.... to the exclusion of creative response or initiative...."[15]

There have been a few studies which have reported on families in which the illness was an occasion to improve group harmony and stability. Intense experiences such as heart disease or blindness have been shown to be followed by radical reformulation of personal values and family life-styles.[16] One study of heart patients and their families, for example, observed: "The single most common characteristic reported by wives (47%) was in the husband's personality or characteristic mode of behavior." The authors went on to say that some family members "saw the illness as being the avenue to a larger fuller life than they had before..."[17]

What in the social organization of such families or in the social context of the illness caused such favorable outcomes has not yet been a subject of much sociological investigation. Some time ago Angell[18] suggested that families which avoided the disorganizing effects of crisis were "well integrated" and "adaptable." Yet as Hansen and Hill comment, research has not led to a solution of "Angell's difficulty of defining, in operation and theory, the components of integration and adaptability. The problem remains unresolved today."[19] While the present study of eight families cannot resolve these issues, it may provide the data on which to base hypotheses for future investigation.

Initiating the family crisis was acute myocardial infarction (heart attack), which occurs when the flow of oxygen and blood to the heart decreases severely and causes death of heart tissue. One medical textbook defines myocardial infarction as resulting:

> ...from deficient coronary arterial flow to an area of the myocardium with eventual celluar death and necrosis. It is characterized by severe and prolonged precordial pain similar to, but more intense than, that of angina pectoris...[20]

The onset of this illness engenders a situation at once amenable for study, of rapid redefinitions and problem solving, and also in its chronicity, relevant for consideration of the long term effects of a spectrum of illnesses that account for the large amount of medical service today. Heart disease, particularly acute myocardial infarction, is a major cause of illness and death. In 1973 out of 1,973,000 deaths from all causes in this country, 1,037,592 were caused by major cardiovascular disease of which 351,662 were myocardial infarction deaths. In persons between the ages of 50-69, there were about 600,000 deaths from all causes in 1973 and over 140,000 of them were caused by acute myocardial infarction. Looking at the problem on a more local level, there were 31,130 deaths from acute myocardial infarction in New York State in 1973; 95,415 deaths from major cardiovascular disease; and 181,287 deaths from all causes. In men aged 50 to 69 there were 57,481 deaths from all causes in 1973 in New York State and about 21,000 were due to myocardial infarction.[21]

The Focus of the Present Study: Process and Structure

The data for this study was collected at the time the families were living through the crisis. Research activity began shortly after the patients were admitted into the hospital's Intensive Care Unit and ended five months later. While this study may be seen as a response to a need to understand factors influencing behavior in families following serious illness, its framework addresses a particularly neglected area of research recently identified by Berman: "The territory of family stress" he claims, "is almost uncharted with respect to interactional process in the face of disruptive forces.... Observational, naturalistic data are badly needed."[22]

Interviewing and observing families regularly during the course of the illness and its aftermath can not only show where change takes place in the family routine, but also whether it will be long lasting. Moreover, the consequences of crisis-induced change become apparent once one follows the development of strategies for dealing with the management of the care, and responses to unanticipated situations which, as Hill[23] theorizes, regularly occur throughout a period of crisis adjustment. Studies which do not control for time and stage of response have limited value. Speaking of their own study in which childhood illness was associated with parental disharmony, Crain, Sussman and Weil observed: "Unfortunately, an uncontrolled variable in this study is the length of time between onset of illness and the measurement of parental and child behavior.... If the reaction to crisis assumes a roller coaster pattern one would expect to see differences among the families based on the time elapsed since onset."[24]

The results of this exploration of family life in particularly trying circumstances demonstrate how family structure and values influence attempts to adjust, regroup and cope with the exigencies of the crisis. Parad and Caplan found that: "When the family faces a stressful event, its lifestyle (role system, value system, and communication network) places at its disposal a range of problem solving possibilities from which the family members individually and collectively may choose according to their perception of the demands of the situation."[25] While the families under examination in the current investigation showed similarities in socioeconomic status and stage of family lifecycle (middle class, and either preretirement or early retirement under Troll's[26] categorization of family lifecycle) there were significant differences among them in terms of organization of the division of labor and patterns of communication and affective relationships. The analysis will show how variations in family structure and values are associated with patterned differences in coping response over time. Hopefully, the resultant model of response to crisis will facilitate the prediction of the circumstances which can overwhelm a given family's capacity to adjust and avoid severe disorganization. At various stages of the crisis some families may show surprising strength while others cope badly with the same set of problems. This research aims to demonstrate how such variation in response is not a random phenomenon but corresponds to structural and cultural differences among families.

Questions concerning patterns of family organization and their relationship to family functioning often initially center on two central processes: The family division of labor, and patterns of companionship. These processes reflect the way family members choose to be together and apart, and how the family maintains boundaries between itself and the outside social system.[27] How a family has decided to structure its inner organization can determine its response to events which threaten disruption of normal behavior patterns.

The family division of labor refers to the roles that are assigned to family members in order to accomplish essential tasks in the home. Generally, family roles may be differentiated so that each member has responsibility for a defined set of tasks, or roles may be shared or exchanged among several family members. Often, as Goode points out, "the division is not based on a rational judgement of capacity." Rather, "the division (of family responsibility) is justified by various rationalizations and by moral precepts...."[28] That is, the role structure reflects an underlying value and belief system about relationships between husband and wife, parent and child. To attempt any alteration of such relationships would entail touching upon matters which are imbued with strong sentiments.

Family companionship refers not only to the quantity and quality of intrafamilial communication and expressions of mutual affection, but also to norms and behavior patterns with regard to kinship and external social networks. The nature of participation of family members in outside groups and interests may suggest something about family relationships. On this point, studies have demonstrated that participation in external groups and interests is related to marital stability.[29-30] The direction of the relationship, however, is at this time unclear. Nevertheless, it is clear that for some families the marital dyad is supported in part by friends and relatives. Scanzoni's position is that, "Consensus over goals and means comes chiefly through voluntary, natural participation in external networks and interests. To the extent that the couple is mutually integrated into these external networks, it will share common values and norms, hence resolve conflict by means other than dissolution, and thus remain organized."[31]

In Bott's[32] analysis of family and social networks it is suggested that separate participation by spouses outside the family will not necessarily weaken the marital bond. Studies by other sociologists confirm this. They point to families in which fulfillment of instrumental needs is critical to marital stability, and companionship is not strongly desired. In this socalled "institutional family"[33] emotional satisfaction is derived for each spouse through participation in external networks, and marital stability seems to be a function of compatibility between role expectation and performance in instrumental activities.

These are areas of family life that illness can have an impact on. For example, in a highly differentiated family where rigid sex and generational roles prevail, considerable strain might follow when the recovering patient - who is the family's breadwinner - is expected under the norms of the therapeutic regimen to be passive at home while his wife and children assume active roles with regard to supervising his behavior, and in replacing him in the family role system. If, however, strain had already existed due to some person(s) being dissatisfied with existing role assignments, the new responsibilities, sanctioned by medical necessity and reinforced by the authority of the physician, could increase the satisfaction of some family members. In another type of family where role sharing is both valued and practiced by all the family members, tension caused by reallocation of tasks might, hypothetically, not be high. But strain could develop in this kind of family once the need for members to assume the specialized roles of patient-medical surrogate became more than a temporary state, because this is a form of relationship which, in its highly differentiated form, is at odds with the way people in the family desire to interact.

In families where patients are convalescing at home, others may feel required to focus their time and energy more extensively and intensively inside the boundaries of the home than they had previously. Opportunities for interaction in and outside of the home will change. For some, this might be a welcome chance to demonstrate love and enhance group solidarity. For others, however, this could be a stressful period due to conflicting loyalties - to the family and to outside interests. Spouses who normally participate separately in social networks and derive important emotional support from their outside activities might find it difficult to reduce such participation.

In the following chapters these issues will be discussed. As we will see, the pre-illness patterns with regard to companionship and the division of labor do affect the reorganization of the family in crisis. Families in which members value "separateness" in internal and external activities perceive and solve problems differently than do families which thrive on "togetherness." Not only do interpersonal relationships vary among different types of families, but the pace of the rehabilitation is also influenced by family goals, values, practices and relationship.

Learning Social Roles for Hospital and Home Care

When people are told by a doctor that the pain which brought them to seek medical consultation is indicative of serious illness and requires immediate hospitalization, the reaction is often one of surprise and frightened apprehension. The evidence suggests that the person experiencing deepening physical discomfort tries hard to explain it as being the result of some non-serious condition which causes minor distress from time to time.[34] The pattern seems to be that before considering that the symptoms might mean new illness, or a significant worsening of an old one, people attempt to apply all the remedies which worked in the past. Only when these are exhausted is the decision made to seek medical advice.[35] Reports of interviews with hospitalized heart attack victims and the members of their families point out that people sometimes live for days with severe chest pain while seeking relief through over-the-counter flu tablets, or muscle relaxing ointments.[36] Right up until the diagnosis of heart attack is told to them, the suffering person and members of his family often hold tenaciously to the hope that the illness will require minimal medical attention. Most studies which have dealt with delay in seeking medical care have not focused on the type of medical care system the patient used. One of the claims made for prepaid group practice is that with no financial disincentive to seeking medical attention, patient delay may be reduced. When we examine how our eight patients sought help for their symptoms, we will be able to comment on both the social structural and social psychological components of defining illness and seeking medical help.

For the above reasons, and because heart attacks can strike with little forewarning, patients and families are usually ill-equipped to manage the initial shock of crisis onset. In time, as studies point out[37,38] events prior to the attack of illness are reconstructed by the victims in such a way as to make what happened to them appear the obvious result of a series of actions. Thus, the illness appears less mysterious and more amenable to rational intervention to prevent its reoccurance. But at onset, the typical experience is that the illness came "out of the blue," since "he's never been seriously sick a day in his life."

In contrast to the need of patients and families for information with which to define the situation, medical personnel from whom help is sought are prepared with information, explanations, and standardized patterns of action. Moreover, they are prepared to convey prescriptions for behavior to patients and families-of-patients while the treatment is in progress. As Lorber[39] points out, however, medical personnel in hospitals give information and direction to lay people not for their convenience or illumination but to maximize the smooth operation of the organization. What patients and family members are told, and are allowed to see seems to be related to the medical staff's desire for ease and convenience on the job. As a consequence, people often discover during or after hospitalization that they have not received adequate information.[40]

A number of sociological studies have documented that hospitalized patients desire more information about their care than they are given,[41,42] yet are often unable or unwilling to effectively seek it. Sometimes patients do not demand explanations from staff out of a fear that the care will suffer.[43] Explanations from doctors and nurses can be so technical as to be unintelligable to the layman, and when a patient receives conflicting information from members of the staff, he often ceases direct inquiry. Lorber argues that "the more like a helpless object the patient becomes the easier (the medical staff) find it to do their job.... the routinization of work is helped when the patient is objective, instrumental, emotionally neutral, completely trusting and obedient."[44] The patient who does not quietly submit to hospital routine but demands more knowledge of his condition or of the treatment process is often considered to be deviant in the eyes of the staff.

In attempting to control the flow of information to the patient and the family of the patient, the staff can call upon its professional prerogatives.[45] Laymen are not expected to understand the complexities of the care. Submission to professional authority is a central component of the sick role.[46] Professionals also utilize what Davis[47] has termed "functional uncertainty." The circumstances under which the physician claims to be less certain about the patient's condition then he actually is occur when he desires "to reduce materially the expenditure of additional time, effort, and involvement which a frank, straightforward prognosis to the family might entail."[48] Davis adds that a significant proportion of what physicians tell their charges is in the service of having them accept the socially and physically disadvantageous consequences of illness. Not the least of the measures by which medical staff can manage what is transmitted about the illness and treatment is the control it has over the actual hospital space the patient and family have access to. By confining the patient to a particular setting, or what Goffman calls a region, i.e., "any place that is bounded to some degree by barriers to perception,"[49] the staff is enabled to censor what passes through the spacial boundaries to create a desired impression.

In situations where the acute, in-hospital phase of illness is followed by a recuperation period at home, as was the case for the eight families in the present study, perceptions of the illness among family members are likely to have an affect on long-term adjustment. It would seem apparent that for effective management of home care, family members should have an accurate understanding of the illness and thorough knowledge of what the patient needs in the way of care. This is expressed in the "mutual participation" mode of physician-patient relationship put forward by Szasz and Hollender. "This approach is often useful," the authors explain, "for the management of chronic illness in which the treatment program is carried out by the patient with only occasional consultation with a physician."[50] Here, the orientation of the patient, and those at home, is expected to be active. Their response must go beyond following doctors orders, to include interpreting what they are told and developing an ongoing set of routines to implement the medical guidelines. Mutual participation also implies that the quality of guidance the physician supplies to the family is determined in large part, on the feedback he receives from the patient and the family.

The literature on the recovery process following serious illness demonstrates that inadequate or incomplete information is often at the root of a patient's difficulty in normalizing his life. Duke[51] has observed that physicians are often over cautious, that is, they advise less activity than the patient can safely handle, slowing up the rehabilitation, because they perceive that this is what the family expects due to popular conceptions of heart disease. He goes on to speculate that fear of family recrimination should the patient not respond to the treatment adds encouragement to the physician to create a regimen consistent with the imagery of a heart attack victim held by the family. Another study of advice given by physicians to heart patients on sexual behavior reported that in spite of numerous findings that sexual activity is not detrimental to a patient with a heart condition, physicians commonly advise against this activity and deprive the married couple of a vital activity.[52]

The work of Klein and his associates[53] suggests that the "cardiac cripple" phenomenon can result from a failure of the patient-physician, or family-physician relationship to develop beyond the early critical stage of care where the patient in the Coronary Intensive Care Unit is expected to be passive and non-autonomous while the medical staff of experts is active. Some patients experience this situation in a profound way and come to believe that they are safest when most inactive and closest to medical support. They define themselves, and their spouses do likewise, as vulnerable to relapse and in fragile health even as their medical chart indicates that health and strength are improving. The study showed that physicians attending the patients were generally unaware of such negative attitudes and therefore did not direct any effort to correct them. In Fred Davis'[54] study of young polio victims and their families, children experienced in the hospital a high degree of attention from the staff who infused the childrens' environment with numerous rewards to induce conformity. Once home, these same children demanded from their parents and siblings the same level of attention. The result was a generally painful period for parents and children alike as they had to readjust their expectations and behavior. In this same study, medical staff were found to hold the opinion that knowledge about the extent of permanent disability from illness was better discovered by the family members themselves gradually rather than by direct communication with staff. Physicians claimed, incorrectly, that they were uncertain about the prognosis for full recovery. The consequences were that hope on the part of the family became exaggerated and time was lost in the beginning the process of physical rehabilitation.

The present study attempts to make a contribution to our understanding of how the hospitalized heart patient and his family defines his illness. The data will show how perceptions of the care process are structured, and then how they can affect chances for successful adaptation to the situation after the patient returns home. Talking with, and observing patients, family members, and medical personnel as the care process unfolds adds a uniqueness to this study. Other research into how definitions of the situation emerge among patients has largely taken a retrospective approach.[55,56] I did not have to rely solely on past reconstructions of what the patient and his kin experienced.

Because hospitalization separates patient from family, especially during the stay in the Intensive Care Unit, questions for analysis included: Did patients and the members of their families share the same perceptions of the situation? Did they agree on what caused the problem, and how to avoid its reoccurance? Did they make the same observations of the care process - and come to the same conclusions about it? If they did perceive the illness and the care requirements differently, how did patients and their significant others resolve the differences? In the chapters to follow these issues will be addressed.

The Relevance of the Care System

The setting for the study provides an opportunity to examine the inner workings of a health care system: how it moves patients from one level of care to another, its mechanisms for integrating hospital and home care, how it prepares a patient to re-enter his social world. As any good analysis of the delivery of health care would do, this study will make note of the contributions to patient and family adjustment made by different levels of the professional staff, and the problems patients had in interpreting the actions of the whole staff. Moreover, we will see how formal rules and procedures of the organization could be misleading to people unfamiliar with them.

The medical care system which was responsible for the patients' care was a Prepaid Group Practice. In its structure, this form of health care delivery departs dramatically from the more familiar solo fee-for-service practice. Rather than paying for each service obtained, members of prepaid group practices pay a set yearly fee (this is community rated not experience rated: subscribers pay equal rates and the total costs are shared by the population of subscribers) regardless of services performed by the Group, including all hospital care. Physician members of the Group, many of whom are joined in a legal partnership, receive payment for their services on a capitative basis rather than a fee-for-service basis. The Group provides centralized facilities for lab work and specialist referrals are made mainly to other group members.

While group practices provide only a fraction of the total health care in this country their development has shown significant growth recently. In 1946 there were 368 group practices. In 1969, this figure increased to 6,173.[57] Moreover, the Health Maintenance act of 1973 has provided stimulus for further development of the group practice model.

Impressive claims have been made by proponents of group practice about its potential for providing a superior form of health care. Mechanisms for effective and efficient service delivery are supposed to be built into the system. For example, the prepayment scheme should eliminate the financial barrier to decisions to seek medical attention for symptoms of illness. Moreover, attention to preventive health care is a central claim of group practices. Saward argues that capitation payment to physicians "involves the reversal of the conventional economics of medical care....Prevention, health education, and early disease detection are obviously good for the population covered but can also be a cost saving to the providers."[58] Cutting contrasts this with the traditional fee-for-service model. "It has always been a paradox that doctors and hospitals are dedicated to helping people well and healthy, yet generally derive most of their income from illness. By contrast, when prepayment is made directly to the providers of care, both the hospitals and the doctors are better off if the patient remains well."[59] This concept should apply both for the prevention of new illnesses and the reoccurrance of acute instances of chronic illness.

Other advantages that have been cited for group practice include the ready availability of diagnostic tests and specialists. Cutting proposes that "the patient can relate all of his health needs to one medical center, knowing that his physician has complete inpatient and outpatient facilities, equipment and services readily at hand at all times."[60] The argument goes that when a patient's condition requires treatment by specialists, when the care requires different levels of treatment, an organized, multispecialist medical group facilitates the coordination of care, and eliminates episodic and fragmented care.

One of the criticisms of solo practice is that often the patient is not in a position to evaluate his care, and there are few mechanisms for professional peer review at the individual practitioner level. In contrast, it is claimed that, "In a group practice each member's work is open to scrutiny, patients are exchanged, and charts are frequently reviewed in the course of practice. Earning the respect of one's peers stimulates individual physicians to perform at a high level."[61]

Social scientists have challenged some of these claims, however. Freidson[62] studied one group practice's methods of regulating and controlling the everyday practice of its physicians, and of responding to sub-standard performance. He reported that technical performance is generally unobserved, uncommunicated, and uncontrolled. Only the most blatant form of incompetent behavior on the part of a physician would bring forth sanction from the group. Traditional conceptions of professional autonomy prevailed.

Questions have also been raised about whether a highly bureaucratized system makes it easier or more difficult for health consumers of all backgrounds to utilize the services. While the physician in solo practice may not have as wide a range of services as readily at hand as his colleagues in group practice, his patients have to deal with a less complex source for care. Roemer and his associates[63] have cited "complexities of operation" as a barrier to the more sophisticated (in his study: lower social class) in utilizing group practice medical care.

At Medical Group, once a patient enters Group Hospital his care is planned and carried out by specialists who are assigned there. The practitioners who serve as families' primary physicians in the community and coordinate their ambulatory care needs have no responsibility for the care of their patients in the hospital. Under the traditional health care model patients' private physicians often do. Except for the time patients stay in hospitals' intensive care units, their private physicians are able to care for them for the duration of the hospitalization and then continue with the management of care at home. Under the medical Group system, the family's primary care physician is expected to take up patient management after hospitalization. Yet, as I shall explain in greater detail later, patients and families sometimes took this arrangement to mean that their primary care physician was not adequately trained to provide care for heart attacks. This perspective interfered with patient and family responsiveness to the home care regimes.

As will be discussed in the following chapter, other problems people had in understanding the system of care involved the medical residents at Group Hospital. These new doctors spent six weeks of their residency training program at Group Hospital. Prior to coming there they trained at hospitals which operated under the traditional model. Based upon what patients and family members told me, and what I observed, residents did not always have a firm grasp of how inpatient and outpatient services were supposed to be co-ordinated in Medical Group. Some misinformation was conveyed by them.

Methodology

This study reports the experiences of eight families in which the normal course of living was suddenly interrupted and significantly altered by the occurrance of heart attack to the husband-father. The analysis of the way the family members coped during the first five months (approximately) following the onset of the illness is based on data gathered by open-ended interviewing and participant observation.

In several places in this introductory chapter I have indicated that despite past research by sociologists and others, important questions about how families cope with a crisis like serious illness remain unanswered. Data which is collected at the time the crisis is unfolding is particularly in short supply. These conditions warrant a study of the problem which can supply the field with detailed information about the process of coping and the dimensions of social structure which underlie its development.

Case studies are particularly useful when comprehensive, in-depth and first hand knowledge is needed for a fresh look at a problem. Hess and Handel state that:

> The detailed examination of cases suggests lines of thought, urges re-examination of contemporary thinking, reveals areas of behavior in which our knowledge is sparse, and stimulates hypotheses that may be tested in other research formats.... Case studies have, perhaps, a particular usefulness when they deal with problems at the forward edge of an area of investigation. They make it possible to illustrate in detail the referents of new concepts and to think about their ramifications.[64]

Case studies have been utilized for analysis of family dynamics in a variety of situations. Berman's[65] was an account of a single family's response to the approaching death of the mother; Lewis[66] looked at one extended family's reaction after the death of a member; Henry's[67] five families elucidate the relationships which might have contributed to the severe mental illness of a child; Hess and Handel[68] interpreted relationships in five "normal" families; the Rapaports[69] described the division of labor in several families where both spouses had full time careers. In each of these studies, all family members are important sources of information about everyday events in the home, including the activities which numbers engage in individually and together, the problems which arise among the members, sources of satisfaction and reasons for dissension and conflict, relationships with other groups. The results of these in-depth explorations provide explanations of how families work in ordinary and special circumstances. The choice is for a holistic understanding of how various components are interrelated in a single unit, and how the particular arrangement functions to satisfy individual and group needs. Often, families are chosen for comparative analysis because they represent alternative forms of organization. Case studies cannot make claims for the ability to generalize from their data to large populations. But they do suggest the consequential factors, which might account for similarity and difference among many families. They are useful for construction of ideal types, providing subsequent research with hypotheses firmly grounded in empirical observation.

In choosing eight families I had a small enough group so that I could study each one intensively for several months, and still have enough families to do comparative analysis. The selection criteria were:

1. No patient will be over 65 years of age, or be nonwhite.
2. No patient will have had a previous heart attack less than 5 years prior to the current one.
3. Each family will be intact, i.e., both spouses present.
4. Each family will be clinically "normal" in the sense

that none will contain a mentally ill member.

5. The families will be selected in the order that they present themselves to the hospital.

As soon as was feasible considering the stress the families were under after the heart attack, all family members were interviewed about practices which have been an essential part of their daily lives, and their value assumptions. The schedule for initial interviews is adopted from Hess and Handel,[70] who made an early conceptualization of the field. The topics include:

1. Each member's view of his family - what it is like, what the important things about it are.
2. The family's daily life - what they do and how they feel about it ....
3. The work and responsibility roles of each member... the assignment or assumption of household management responsibilities....
4. The course of the family's development... their goals, aspirations, regrets and disappointments....
5. The socialization of the children... what behaviors they consider to be offences and how they are handled.
6. How the members perceive and feel about each other...
7. What problems each member feels he has in relation.... to other family members.

I collected this information in the early stage of the crisis to maximize accurate comparison of precrisis family patterns with adjustments made during the crisis.

Prior to selecting families I spent several weeks at Group Hospital to become familiar with the procedures for treating coronary patients, and to give the medical staff a chance to become acclimated to having an observer present on the medical units. In my role as observer I actually saw heart patients admitted to the Intensive Care Unit and watched as they were oriented by the staff. However, I only began interviewing after I had obtained a signed consent from the patient and each member of the immediate family.

I interviewed the hospitalized patients at least once a week, and arranged to be present inside the hospital for long periods of time, sufficient to allow me to engage some of them in informal conversation around what was happening to them. I attended morning medical rounds - where each patient's case is reviewed by a group of doctors at the bedside. Also, the long and frequent observation periods in the hospital while my study patients were there allowed me to see first hand the events which occured to, and around the patients, and their interactions with medical staff, and each other.

During each patient's period of hospitalization, I also tried to interview the members of the family once a week. This was not always possible. Some interviews took place in the home, others in the hospital. I had additional informal contact with the families during their visits to the hospital where I observed patient-family interaction both in the

Intensive Care Unit, and later in the General Medical Ward.

After the patients left the hospital, I continued to visit them and the members of the families at home. I tried to arrange for home visiting at least once every two weeks. Sometimes the family schedule did not allow for this frequency. On the other hand, there were periods when I had contact with families weekly. I explained to the study participants that I wished to speak with them separately. and also to be present for some joint family activities. This was accomplished with each family, although the extent to which I was able to observe informal, spontaneous family behavior varied from group to group. Sometimes family members called me between visits to inform me of some new development.

My questions to the family members were open ended to allow the most freedom to express what the individual perceived to be the salient aspects of post hospital family life. For example, the interviews included the following type of information:

- Each members' view of patient needs and progress. Current problems and barriers to health and ability to follow the medical regimen as it is understood in the family. Attitudes toward the treatment plan.
- Perceptions of patient role behavior. How the patient actually carries out the medical regimen. How decisions are made to alter it or increase his activities. The factors which in the eyes of the members encourage

or discourage rehabilitation progress. How the patient perceives himself as a person and a family member during the course of the illness and rehabilitation.

- The family's daily life now. What are the routines and schedules in the home? How adequate do they appear to the members; where are the points of inadequacy? What does each member do at home - with whom and for what purpose?
- What are the roles and responsibilities of each member and how do these reflect the illness? How is household labor divided and what are the criteria for allocation of tasks?
- What problems do the members feel they have with other members now? Are these new or continuous with the pre-illness pattern? What hostilities are experienced in the family, the issues, circumstances and conflict behavior and resolution?
- The outlook for the future. Critical events coming up. Plans being made and altered. The direction the group feels it is going in and the steps it is prepared to take to achieve future goals.

Personal contact on a regular basis with the families was an important component of the research method. The people were living through an intense and difficult period. The decisions they were faced with had implications for the success of the medical therapy, and for the quality of the family bond. It was difficult for people to know what problems would arise as the crisis unfolded. At the same time they were being asked to reveal their experiences, both good and bad, to a virtual stranger. I decided that if I was going to learn an accurate account of life inside their families, the members would have to understand the purposes of this research, and perceive the researcher as someone who could be trusted and who was concerned with them and their problems. Personal contact with the people seemed essential to this end.

In contrasting fieldwork with survey methodology, Sieber points out that "Detailed and indirect probing may bring to light unfavorable facts which are not readily admitted in direct questions and in surveys."[71] By my frequent presence in the homes I could probe into important events from many sides, follow their natural development and assess ramifications for future behavior. I obtained accounts of what was happening from each member and thus learned the variety of definitions of the situation which existed in the home, and how they led to solutions to problems or to interpersonal antagonism. I would add to Sieber's statement that observation and open ended interviewing is uniquely appropriate for studying a group during a period of transition because the researcher himself increases his understanding of the situation as the action unfolds. As the researcher gains in awareness of family patterns, he can go back over his data to correct earlier misconceptions and wrong directions, or he can substantiate initial impression and working hypotheses. Questions asked and observations made become more pointed and relevant to the significant features of family dynamics.

People who are the subjects of study often help the researcher focus his observations and interviews. Once the members of the Norton Street gang[72] and the men who gathered on Tally's corner[73] accepted the researcher's presence among them, they gradually became partners in the research act. They often pointed out important events which the researchers had overlooked, and helped correct interpretations of action which did not fit their cultural pattern.

In a similar fashion, as my own study progressed the people I was studying became increasingly active in suggesting significant occurrances for us to discuss. Moreover, mutual familiarity led to an increase in access to the private domains of their families.

Data Presentation

The findings of the study will be presented in chronological fashion. Chapter 2 starts with an account of problems the patients encountered in the time between the decision to seek medical help for their symptoms and their arrival at the hospital's emergency room. It reports their experiences as patients in Group Hospital's Intensive Care Unit, and discusses the development of definitions of the situation during this acute phase. Comparisons are made between patient-family-medical staff perspectives and attitudes toward the illness and the care process. Implications of this setting for adjustment in the next phase of care are drawn.

Chapter 3 is set in the General Medical Ward. It discusses how patients and family members prepare for the return home, and learn how to care for the illness at home. As in the preceding chapter, the importance of the social organization of medical care at this level is revealed by the way the setting can enhance or block opportunitities for patients and families to understand the illness and its treatment.

Chapter 4 introduces the families as social systems. A fourfold typology is presented based on the variables:Division of Labor, and Companionship.

Chapter 5 begins the analysis of the effect of family structure on the process of care and adjustment in the home care phase of treatment. The first two stages of home care are presented. Life at home will be contrasted for families of different types. Implications of the families' structure and culture for patient role behavior and compliance with the medical regimen will be drawn.

Chapter 6 deals with patient attempts to recover normal social participation. Again, the role of the family in this process will be seen to be highly significant. In the third stage of home care, the relationship between family structure and secondary gains from the illness will be discussed in terms of its ability to explain family disorganization during an illness crisis.

Chapter 7 is the conclusion. The implications of the study for the development of a social theory of family-in-crisis will be stated, as well as suggested directions for further research.

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Chapter 2

Crisis Onset and Emerging Definitions of the Situation

I. Biographical Sketches

The events which I will describe occurred in eight families who lived in the residential section of one of the largest cities in the nation. At the time of the attack, each of the men held some form of income producing occupation, although for the retired this was generally in a part-time capacity. Their ages ranged from fifty-two to sixty-five. All were white. Over half of the men were, or had been, employees of the city in which they lived, and all had their membership in the prepaid medical practice, which I call Medical Group, paid for by the employer.

Six of the families gave their religion as Catholic, two as Jewish. Only one couple had been previously married, the first marriages ended with the deaths of spouses. Three families had at least one child living at home.

Throughout this thesis I use pseudonyms in place of actual family names. The following are brief biographical sketches of the families.

The Ambrosio Family:

Mr. and Mrs. Ambrosio are in their sixties. He is retired from the civil service where he held a middle management position with the Fire Department. He remains active as a consultant to private business in helping them comply with fire safety regulations. Mrs. Ambrosio is a former school teacher, and occasionally works as a per diem substitute teacher in the neighborhood schools. The couple has two married children, and live in a comfortable home in one of the city's residential districts.

Prior to his heart attack, Mr. Ambrosio had no history of heart disease. However, he was diabetic, on medication and a special diet. He claimed that he often did not strictly adhere to the diet regimen. About eight years ago he required surgery for the removal of his gall bladder. He said that in the past year he had more minor ailments - colds, flu symptoms, etc. - than he remembered having before. However, he maintained his active daily schedule and continued his long time habit of sleeping only four hours a night.

Mrs. Ambrosio's most significant health problem is osteoarthritis, a degenerative joint disease which, in her case, affects the lower back. She and her husband have used the same family physician for over ten years. Occasionally, she is unable to carry out her full schedule of activities because of pain and stiffness. Most of the time, however, she reported feeling strong, healthy, and energetic. She said she looked forward to her "golden years" bringing increased opportunity for travel, and companionship with her husband.

The Grasso's:

Mr. and Mrs. Grasso are in their fifties. He is a retired city police officer, and presently operates a family owned card and gift shop in the neighborhood where he lives. Mrs. Grasso works four days a week in the clerical position for a large corporation. They own a two family home and rent the upstairs apartment. The couple has one married daughter, and a son in his early twenties who recently has returned to live at home after a divorce. They have a very close circle of friends who they see several times a week, and in addition they maintain strong ties with their kinship network.

Six years ago, Mr. Grasso suffered a heart attack. He reported that he has not been following his prescribed diet strictly and has resumed smoking regularly. His habit of doing strenuous activity, and smoking, has been a source of disagreement with his wife. In the year prior to his current heart attack, he saw his physician very infrequently, but claimed he was feeling well. His family has used the same physician for over ten years.

Mrs. Grasso has no chronic ailments, said she, and enjoys an active life - especially visiting with family and friends. Prior to the heart attack, the family was just recovering from the traumatic effects of the son's divorce and were upset by the prospect of not being able to enjoy their new granddaughter's company as freely as had been anticipated. Mrs. Grasso said her husband had taken this very hard.

The Warren's:

Mr. and Mrs.Warren are both retired and in their early sixties. He was a mechanic for the city's department of transportation; she worked as a secretary. Now, Mr. Warren drives for a private car service one day a week. His wife does not work at all. The couple have no children. Both said they lived a quiet life, and although they are both home often, do not often spend time in joint activities.

Mr. Warren's major medical ailment prior to the heart attack was a hiatus hernia, which affects the stomach through the esophageal hiatus of the diaphragm. The major consequence of this, according to him, was occasional indigestion. Mrs. Warren described herself as in good health, with no active debilitating ailments. They too have received their medical care from the same physician for almost ten years.

At the time the heart attack struck, the Warren's were in the process of purchasing a new home in Florida.

The Asti's

Mr. and Mrs. Asti are in their late fifties. He is employed by the department of highways as a maintenance supervisor. Mrs. Asti is a housewife. Presently, she is seriously considering returning to work with a garment manufacturer where she was employed early in her marriage.

The Asti's have two children living at home: Rose, a twenty year old college student, and John, a twenty year old construction worker. A third child is married and lives in an apartment in her parents' home. The family maintains close ties with relatives, several of whom live in the neighborhood, However, much of this contact is carried on separately, by individuals, rather than jointly by the family as a group.

Mr. Asti has a history of hypertension for which he once took medication. He stopped because he felt he was better, and has not maintained regular physician contact. In the month prior to the heart attack he said he felt quite well and kept an active pace, both at work and at home. Mrs. Asti said she had no health problems, and felt good. Around the time the attack struck, the couple was planning a vacation trip to Florida. Since they rarely travel, and have never been to Florida, Mr. and Mrs. Asti were very much anticipating this opportunity.

The Polski's:

Mr. and Mrs. Polski are in their early sixties. He is a retired mechanic for the city transportation department. He earns extra money by repairing boat engines at a local marina. Mrs. Polski is a housewife. The couple has one son, married and in the armed forces.

Mr. and Mrs. Polski maintain two households, one in the city, and another in an outlying suburb.

About ten years ago, Mr. Polski was hospitalized for coronary insufficiency which is a condition caused by inadequate coronary circulation, resulting in anginal pain. He claimed that this has caused no limitations on his ability to lead as active a life as he chooses. Mrs. Polski's only medical problem is arthritis in her hands. This can lead to an occasional curtailment of sewing and embroidering which are activities she enjoys.

At the time the heart attack struck, Mr. Polski was heavily involved in finishing the construction work on his suburban home. His son was scheduled to be discharged from the Air Force in a few months and Mr. Polski planned to give him the house as a gift. He felt he was working against a deadline and spent every day of the week rushing to finish. He said that he rather enjoyed the work, even though it took up a great deal of his time and energy.

The Stein's:

Mr. and Mrs. Stein are in their late fifties. He works as a printer. She is a customer representative for an insurance company. The couple have two married children. For the past few years Mr. Stein has worked evenings, and his wife days, with the result being they only communicate face-to-face on weekends. This was described by the couple as not particularly troublesome. In fact, they each claimed to enjoy having time to spend alone.

Mr. Stein is one of those individuals who describe themselves as having "never been sick in my life," and the heart attack was not preceded by a general feeling of being not well. Mrs. Stein, however, had open heart surgery performed in the not too distant past and has been under her doctor's care continuously ever since.

The O'Shea's:

Mr. and Mrs. O'Shea are in their early sixties. His work involves installing advertising displays. He also is a part-time bartender in his neighborhood. Mrs. O'Shea works as a cook in a local public school. The couple live in an apartment and have a 19 year old daughter with them. Two other children are married and another is single but living away from home.

Mr. O'Shea had his gall bladder removed several years ago, and his wife suffers from hypertension. About a week before having his heart attack, Mr. O'Shea went to the doctor complaining of chest pain. An electrocardiogram was ordered for him but he was hospitalized before it took place. An important event the family was anticipating at the time of the heart attack was the marriage of their daughter. Mrs. O'Shea was also expecting a promotion in her job.

The Goldberg's:

Mr. and Mrs. Goldberg are in their early sixties. He is retired from his full time housepainting job, but now takes occasional contracts on his own. Mrs. Goldberg enjoys staying home doing housework. Each has a child by a previous marriage. Both children are married themselves. The couple owns their own home, and rent the upstairs apartment to tenants. Mr. Goldberg is handy at making repairs and this seems to be a hobby with him.

Mr. and Mrs. Goldberg have been in good health, they reported, until the present. Mr. Goldberg went to the doctor several days before being hospitalized for a myocardial infarction. He was given an electrocardiogram and medication was prescribed. At this time the couple were expecting to take a vacation trip to Florida.

II. Seeking Help at the Onset of the Crisis

Heart attacks strike suddenly. The pain is often severe and has been described by survivors as "searing" and like having a steel strap pulled tightly across the chest. It blocks normal breathing, and causes sweating and nausea. Not surprisingly, victims are often frightened, and highly distraught.[1]

In spite of the magnitude of the initial impact of this illness, its victims not infrequently delay seeking medical attention.[2,3,4] Even when friends or family members are with the person when he has the heart attack, considerable time often passes before a decision to contact a physician is made, or steps are taken to bring the sick person to a medical facility. The problem of delay in reaching help for serious illness has been investigated for some time, and is not confined to heart attack victims.[5] One study of cancer patients reported that 45% had waited up to three months before seeking help for symptoms they were aware of; 17% delayed a year.[6] A study of a random sample of patients on a surgical service of a metropolitan general hospital found that 35% of them had delayed bringing their illness to the attention of their physicians.[7]

Most attempts to explain delay have focused on the patient and not on the health care system. By denying illness, or out of fear of treatment, patients have been found to wait before seeking medical help. One commentator writes: "Delay is multiplied determined by psychological, psychodynamic, and emotional factors operating before, during, and after the individual's recognition of a sign or symptom of illness."[8] Yet, in the study reported here, the suggestion is that delay between the time the attack occurred and the patient's arrival in the emergency room at Group Hospital was significantly influenced by misunderstanding the procedures for utilizing emergency services in the Medical Group, which is the setting under inquiry. Also, the routines that clients or relatives were told to follow after they contacted the medical system did little to assist people who were frightened, disabled from pain, and highly confused. In other words, the structure of the situation, as much or more than the individual, caused the delay.

Mr. and Mrs. Polski provide an illustration of the complex of factors leading to delayed medical care. Early on Saturday, Mr. Polski, a sixty-five year old retired municipal worker, felt sharp pain in his chest. Later he reported that he had assumed it was related to a "chest cold." He disregarded his wife's advice to rest. He was working to finish building a country home which was to be a gift to his son. Mr. Polski wanted it ready for his son's discharge from military service. To meet this deadline, Mr. Polski had been working seven days a week - a schedule he reported he enjoyed so much he was seriously considering starting another house building project soon. Ten years before this attack, Mr. Polski had been hospitalized for coronary insufficiency (reduction of oxygen and blood to the heart due to clogging of arteries), and for the past year both Mrs. Polski and her son had been urging the man to have a complete medical check-up.

In the past, when Mr. Polski had cold or flu symptoms, he tried to work as long as possible. But on this particular morning, working made his "cold" much worse. By afternoon, he was forced to lie down, by nightfall he could not move either arm without intense, crushing pain. He sat up all night. Pain prevented him from sleeping or even lying down. The town where he was building the country house was sixty miles from his physician. There was a volunteer ambulance to which the family regularly contributes. Yet, although he thought of calling, he did not, hoping "it would pass." By Sunday morning - hours after the attack - he felt some relief from the pain, enough so he felt he could drive. Over the objections of his wife, who could drive, he took the wheel for the sixty mile drive to seek medical attention in the Medical Center where he was enrolled.

But he did not drive directly to the center or the hospital. Instead the couple went home to wait until the start of their physician's office hours on Monday Morning. I asked why they did not on Sunday go directly to Group Hospital, ten minutes from their house. Mrs. Polski explained:

> We went to see the doctor Monday and he said: 'Why didn't you take him to the hospital right away?' But in the book, and they keep telling you: 'Don't go to the hospital. Call up the Medical Center first and the doctor will come and see you. If you need hospitalization they'll send you there.' That's why we never bothered calling on Sunday, and that's why we waited. Otherwise I would have gone to the hospital. It's convenient from here. I could take him there in the car, which we did on Monday... then I know our doctor is in. Eleven o'clock is his first appointment.

On Monday morning, the couple went to the doctor's office. After an electrocardiogram and examination, the doctor instructed the Polski's to go right to the hospital. They did not. Once more over his wife's objections, the man drove home, put his car in the garage - because his wife "has trouble in the driveway." Only then did he call a friend to take him to the hospital. He arrived about 48 hours after the coronary event.

Another heart attack victim, Mr. Ambrosio, whose work habits were reported to be similar to those of Mr. Polski, had a very similar experience. His pain came on Sunday, and by evening was so severe he could neither sleep nor lie down. His breathing came with difficulty, and his extremities were numbed. He took cold medication - a whole bottle - with no relief. On Monday morning at about eight he decided to notify his family physician. At ten o'clock, his wife called the medical center. I asked why they waited the two hours. Mrs. Ambrosio replied:

> I thought, we thought, the center opened at ten. You couldn't, I guess, get emergency. No, you have to go - I don't know if they have an emergency. Well, we were just waiting for ten for the center to open.

They were told to come to the center where the doctor examined Mr. Ambrosio and sent him to another part of the building for an electrocardiogram. They reported a half hour wait before a machine was available. When the family physician read the results of the electrocardiogram he told the couple "possible coronary, go straight to the hospital." Mr. Ambrosio asked the doctor if he could go home first. The doctor, I was told, adamantly refused. Nevertheless, outside the doctor's office Mr. Ambrosio told his wife to take him home. She recalled this incident:

> So I am walking out with my husband to go to the car which is parked in the lot there, at least 150 or 200 feet away. As we are walking he says to me....'I want you to take me home. I didn't shave....' and (he said he had to do) some other things. So I said, 'I'm taking you to the hospital.' He said: 'I want to go home.'

She won the argument and drove to the hospital. However, Mrs. Ambrosio was not able to control the situation entirely. She told me that the doctor had explicitly stated that Mr. Ambrosio was not to walk from the car to the emergency room once they arrived at the hospital but should use a wheelchair. The following is what happened, as she recalled, when they arrived at Group Hospital:

> I knew where to stop, but there was a truck in front of me, and there were cars. They were tooting and tooting and there was no place at all

> to park. I was in the middle of the street. I was going to get out. My husband opens the door and says, 'Park the car.' I say: 'No, you are not going to walk, I'm getting the wheelchair.' 'Park the car!' he shouted.... That was the end.

He walked to the hospital while she parked the car.

As she recalled these stressful events, Mrs. Ambrosio was sorry she didn't call an ambulance. This would have made the trip to the medical facilities more efficient and less stressful. But since the doctor said to go straight to the hospital, she complied as directly as she could. Not only was there delay, but the problems experienced in getting to the hospital compounded the already serious fright and anxiety the sick person and his spouse were burdened with.

Another man in this study, Mr. O'Shea, also drove to the hospital after an emergency visit to his doctor. He was instructed to go directly to the emergency room, but Mr. O'Shea stopped first to pick up his wife at her place of employment, and his daughter at home. His daughter did the driving, and the trip was punctuated by arguments between mother and daughter over the way she drove. Once at the emergency room, Mr. O'Shea left to get a cup of coffee and when he was called to be examined, his wife had to find him and bring him back.

Getting medical attention quickly following a heart attack, or symptoms of an impending attack is vital. Most deaths from heart attacks are sudden deaths, occurring within six hours of the initial attack.[9] One study reported that 80% of deaths occurred within the first four hours.[10] Several cities across the country have responded to the need for prompt delivery of care to the heart attack victim by developing mobile coronary care ambulances which bring specialized resuscitation equipment to the site of the attack.[11]

Not one of the patients or relatives I spoke with was told to go to the hospital by ambulance. The car ride was often delayed, tense, and conflict ridden.

Altogether, five out of the eight patients in this study contacted their family doctor as the first step in seeking help for their symptoms. In all cases, they were directed to action. The families were, in effect, given the responsibility for bringing the patient to the site of medical care at the time when the condition of the patient was such that even a brief delay could lessen the chances for survival. Moreover, at this time, at the outset of the crisis, the family's ability to function efficiently, with maximum speed, was impaired. Adjusting to new role demands in the emergency situation was accomplished with difficulty.

Although those who went directly to the hospital without first contacting the family physician also experienced their share of difficulty, at least they had only to take one trip, not a second one from the doctor's office to the hospital.

That the patients caused some of the delay in receiving care cannot be denied. In almost every case, there was some effort made to interpret the symptoms - severe and unique as they were - as benign, and related to illness people had experienced and overcome without a doctor's help in the past.[12] Yet without direction and affirmative action from their medical care system, these misinterpretations and attempts to deny illness were left unchallenged. This problem is not one which is unknown to the medical world. Published studies have reported, for example, that people who become seriously ill at night are reluctant to call their doctors and wait until office hours commence the next day.[13]

Relying on the family to take the necessary action can result in disaster. Family structure and interaction patterns can themselves inhibit a quick response. Where the heart attack victim is also the dominant family decision maker, he may reject the attempts by others to assume leadership, as we saw in the examples above. This parallels situations which have arisen in community disasters. In one such disaster, lives were lost in a Southern town because white school children were slow to respond to the instructions from a black adult to leave the burning school building.[14] Another among our study subjects, Mrs. Stein, against her better judgement, obeyed her husband's order not to call a doctor or an ambulance even though he was clutching his chest in paroxysms of pain. When I spoke with her she recalled with great regret her inability to act independently.

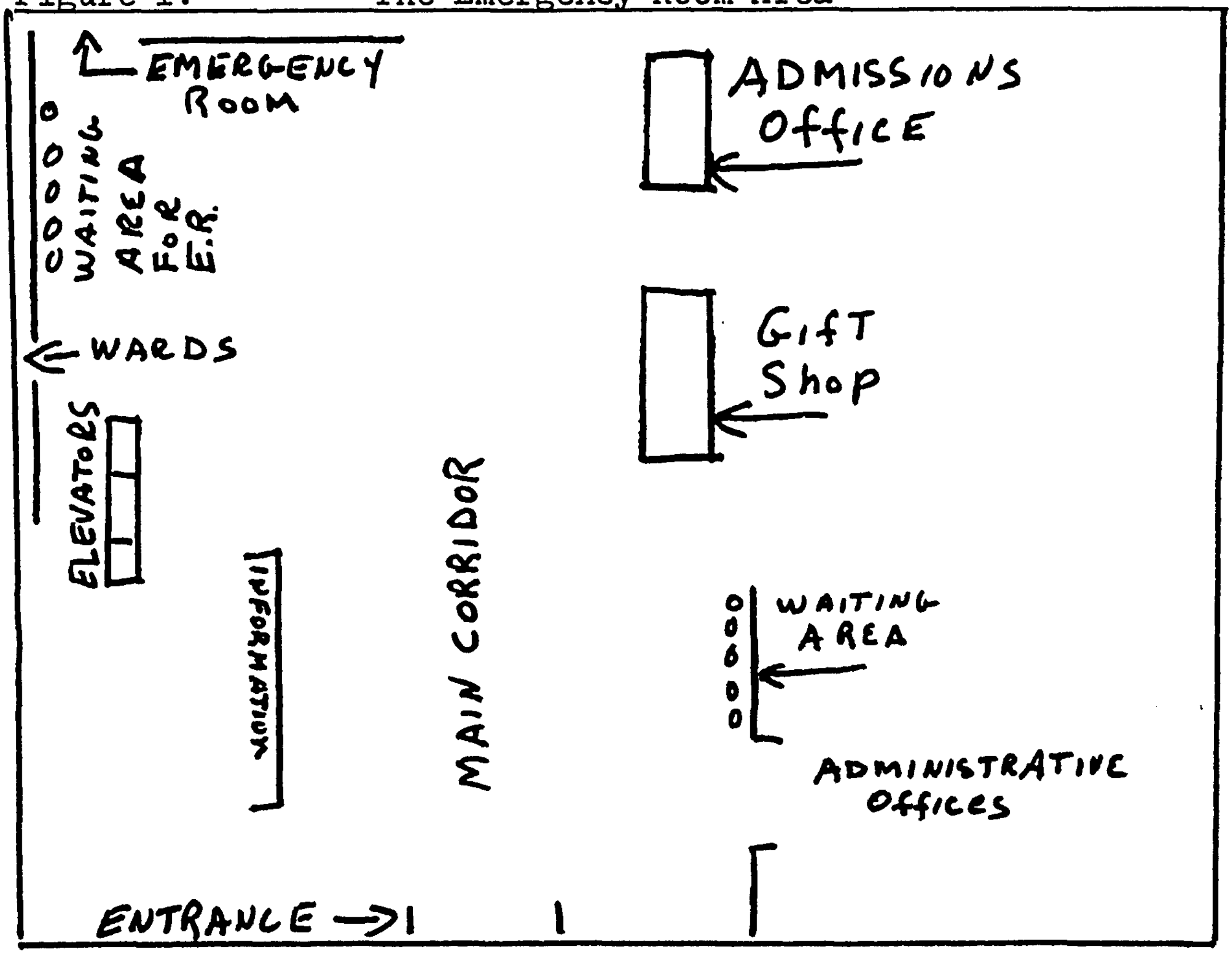
> When we got into the ambulance, when he finally decided to let me call the ambulance, going to the hospital all I could think of is: 'If I had only not listened to him. If I had called at 8:30. If I hadn't listened to him. Why did I listen to him? Look how many hours

> he's suffered. God knows what's going to be with him now! That's all I kept asking myself as the ambulance kept going... As he was sitting here in this chair I should have gone to that telephone and not listened to him. So he would have fought me. He would have said I don't want you to. Still I should not have listened.

When the families finally did act, it was with uncertainty about who to contact or where to go. Moreover, even when heart damage was either discovered or suspected by the family physicians the men were not treated like they were in imminent danger, nor was the fear and anxiety of the relatives taken into account. Rather, they were allowed to leave the area where there were medical experts present and journey by themselves to another care setting.

III. The Setting of Hospital Care

Figure I: The Emergency Room Area



According to the view of several scholars,[15] events which occur as clients who need services enter an institution do much to define the situation for them, especially if the clients are unfamiliar with the role they are expected to play in the setting. Kantor and Lehr have written that as the members of two systems meet, "...those inside each unit use their experiences in meeting members of another unit to define who and what they are as a unit... interface always provides a system with information about the differences and similarities between it and another system."[16] The setting and organization of the emergency room care provided family members with clues to their status in the institution, and some conception of normative behavior expected of them.

The waiting area for the emergency room extended into the main hospital lobby. Family members anxious to hear news of the men they had just brought in mingled with staff and other visitors who were buying gifts, paying bills, grieving, seeking direction, discussing medical cases, joking, crying, etc. The public address system called doctors, and sent them rushing through the lobby.

Family members were not permitted into the treatment area, although some tried to gain access surreptitiously. Mrs. O'Shea tried but left after being "screamed at" by a nurse. Another wife, Mrs. Grasso, whose husband had been in this same place six years earlier with a heart attack, also tried to gain access to where her husband was lying in wait for a doctor to come. Often in the past six years she had feared the possibility of another heart attack. Now that it had happened she wondered: "Will I be left alone?" It was predawn when they arrived and Mrs. Grasso told me that a doctor had to be paged. She thought that it took a long time for him to come. So when she heard her husband call out in pain she went to him. For a while she said she went in and out - going in to comfort the man, leaving because she was afraid of being detected by a staff member.

Each family was given the diagnosis of heart attack in the outside waiting area. Most family members were told the news directly and briefly by a resident. It was followed immediately by instructions that the spouse of the patient should go to the Admissions Office to fill out the necessary forms for insurance purposes, and for internal hospital records. The physician went back into the treatment area.

It was usual for family members to be shocked at being told the husband or father had suffered a heart attack, and needed "intensive care", and not to immediately respond to what they had been told. In spite of the patient's pain and the preliminary tests and ECG results at the Medical Center, they still seemed to hold the hope that after examination and treatment at the hospital, the patient could be sent home with medication and a prescription for bed rest. Family members thought: "How could he have suffered a coronary, he was always so healthy." Mrs. Ambrosio told me, "Dr. B. told me: 'Your husband had a heart attack.' I was still hoping that it wasn't because Dr. M. (the family doctor) said possible coronary. I thought they would just do tests and he would be alright. He said: 'Your husband had a heart attack.' Like, you know, this is it."

With very few exceptions, there were no questions asked of the physicians, who did not remain with the families for very long. No other staff person was assigned to the family at this point. During the few moments that the resident physicians were present the family members seemed unable or unwilling to express their feelings or ask questions. Mrs. Warren, the wife of a patient who refused to go to the hospital in a municipal ambulance because it would not take him to Group Hospital said that the doctor spoke with her briefly after telling her of the heart attack but she could not understand "all the medical terms."

It was in this highly charged emotional state that the family members were left to go to the Admissions Office and then wait to be called to see the patient in the Intensive Care Unit. Only one family member out of some twenty that I interviewed said that she or he was brought out of the lobby to a private space in the treatment area where she could "let it all out." This occurred because the woman in this case insisted, in spite of her perception that the physician was disturbed by her behavior. Mrs. Ambrosio's report of this is as follows:

> I just lost control. Not my husband, no, no, no. It couldn't sink in. He, the doctor, got a little upset that I - - so he said come in. I sat and just let it all out. I said will he be alright? The doctor replied: 'Well, you know, he is pretty serious....'I asked Dr. B. at this time should I let my daughter and son know?' He said that is your decision.

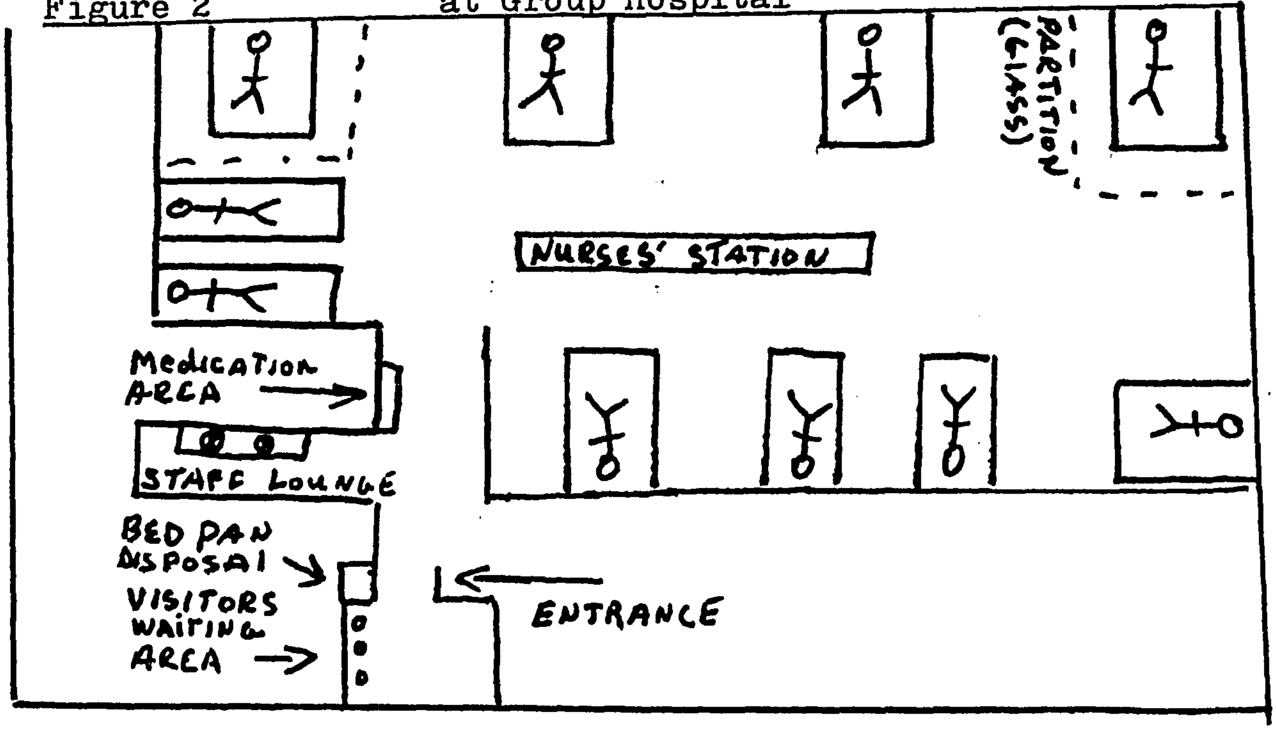
Being inside the treatment area Mrs. Ambrosio was able to seek out other medical personnel for reassurance, and advice on what she should do. She continued, "Dr. K. was there and I said will he be alright? He said: 'Don't worry. He has had severe heart damage but don't worry.' I said should I tell my married children? He said: 'By all means let your son know.' Very very decisive."

When the time came for the families to enter the Intensive Care Unit for the first time they were still very much outsiders to the organization. In the emergency room they had been given no explanation of what to expect, including who was in charge, or whether the patient would survive this heart attack. To this point the family members in the hospital had largely been guided by formal procedures: fill out forms, wait for instructions to go to the Intensive Care Unit.

On my own first visit to Group Hospital's Intensive Care Unit (ICU), I felt very much out of place. Even though I had had a preliminary meeting with several staff members who explained some of the purposes and procedures of the unit, I was not prepared for the sights, sounds, smells and overall tone of the unit. Most often people I observed when they entered the unit appeared very disoriented, as I had been.

The Intensive Care Unit
at Group Hospital

Figure 2



The ICU in this hospital appears like a large studio apartment. Through the windowless front door one must pass through a well lighted foyer containing a kitchenette where staff members make coffee and lunch for themselves, and a table where medications are stored and prepared. This opens into a larger room, the space where nine beds accommodate critically ill patients - those who have had heart attacks or other serious conditions. What one sees and hears creates an instant impression that one is among the seriously ill. Lights flash across a row of heart-rate monitors at the nursing station, a respirator seems to mimic the labored breathing of the patient as it pumps life giving oxygen through his nose and mouth. A patient moans from behind a screen where several medical personnel work intently over him. Other patients lie silently, staring somewhere beyond the room.

Relatives and friends who pass are sometimes weeping.

The unit is kept dark so upon entering one must adjust one's vision. The beds are only five feet apart and for most of the day and night the curtains around each bed are not drawn. Each patient is attached by a TV like apparatus (an oscilliscope - called a monitor) on which the heart rate is displayed and which can be seen from almost any place on the unit. In addition, each patient has a monitor on the table at the nurses station. Because leads which connect the patient to the monitor become loose on occasion, it is not unusual for red warning lights to flash on the monitors. Some patients are under oxygen, all have tubes extruding from their arms and out from under their bedclothes to bottles and metal containers. In different parts of the unit there are large and small pieces of equipment, trays of instruments standing ready. Once inside this unit, there is no place from which most patients cannot be seen and heard. Most of the time 5 or 6 nurses and 2 aides, are present in the unit. But even so the unit usually is extremely quiet except for the many sounds of the equipment and labored breathing. At times nurses can be heard talking together. Patients seldom engage in prolonged conversation - either with a staff member, another patient or a family member.

Coming into the unit for the first time the members of the family typically paused at the nursing station but usually did not address the nurses there. More often, they scanned the room for their husband or father and went directly to him. At the bed, they might grasp his hand, or just gaze intently. Few words were exchanged. In a few moments they left.

What did <u>not</u> happen is significant. There was no systematic routine for introducing the family to the unit. Mrs. Polski's experience was typical:

> They said in the emergency room, that they would call me when they take my husband upstairs, and I could see him for a couple of minutes. So when I came out of the Admitting Room and he's upstairs they told me he's up in Intensive Care. So I went up there and my husband is in bed and they had, what do you call it, a monitor.
>
> (Observer: E. S.) So when you walked into the Intensive Care Unit you walked right over to his bed?
>
> Well, no. Because the nurses are standing there. When I went up I looked around, and I didn't ask anybody because I saw him and I went right up to him.
>
> E.S.: No one said anything to you either?
>
> No. The doctor was right there by his bed too.... He asked how do I feel. I said alright. We stayed for about five minutes.
>
> E.S.: On your way out did you speak to the doctor at all again, did you speak to the nurses at all?
>
> No, I just left. They gave me a booklet(in the Admissions Office) you know, with the visiting hours....If they wanted to tell me something important they would tell me... He (a friend) brought me home. He wanted me to have dinner with them, you know. But I was too tired and I was upset.

If the wife or a son or daughter did speak with one of the nurses it was usually brief. The standard piece of information they received was that the patient's condition would not be known for a day or so, but that indeed he was quite ill. If the person expressed open grief, (this was a rare event), the nurses emphasized that here the patient would be watched constantly and that everything possible was being done for him. On occasion during my stay as an observer, I heard nurses introduce themselves and the head nurse to a patient's spouse. But in the case of the families I followed, and most others I observed, contact on the ICU this first time was very limited in terms of time and family-nurse contact. Some wives were anxious to leave. Mrs. Asti stood by her husband, who seemed unable to speak. After a minute or two she said to her son, "let's go." She said later it pained her to be there. She did not speak to any of the nurses because "they were too busy."

For these wives and children, the entry experience allayed no fears or anxieties. On the contrary, after leaving the hospital they were, as one spouse put it, "shattered." Mrs. Ambrosio felt completely disoriented as to time and place:

> Then I went out and got lost getting home. But I got home - shattered. I just felt terrible...Instead of getting off - I've gone it a hundred times...I should have turned but went straight...I didn't know where I was.

When the family members returned to the hospital that same day, or the next morning, their roles as passive outsiders were repeatedly reaffirmed. The hospital routines, the special arrangement and the temporal patterns, kept the family at a significant social distance from the staff. So far, the family had no way of getting information about the case or the way care was being administered. The medical care system had no way of knowing what impression was being created within the family.

One of the consequences of neglecting to include the families was that a potential source of information about patients was not utilized. Families have a kind of knowledge of their members which the bureaucratic organization does not. They know their idiosyncracies, how they might respond under stress, and what comforts them.[17] The doctors and nursed did not avail themselves of this competence. The roles that the family members were assigned were uniformly passive, as outsiders and onlookers. Nor was there any indication in these early events which would predict that this role would change.

A second consequence was that the family members were denied the comfort of speaking with, receiving guidance and/or reassurances from those whose status as health care professionals is looked upon in our society as sources of help for physical and emotional distress.

The family members, I learned later, did have questions, but didn't ask them. They had doubts but did not express them to the staff. They actually felt that they needed to know what the prognosis and treatment of the patients were, yet did not demand to be told. They waited, to no avail, for staff to come to them. In effect, they behaved in the emergency room and the ICU as they had earlier when they followed without question the directions of the family physicians in their difficult journey to the hospital.

Visiting on the ICU was permitted for fifteen minute periods five times a day. If the patient was sleeping, or in discomfort, or occupied with any medical routines during the assigned visiting time, families were not allowed to enter. Outside the unit, where the families waited there were few amenities or comforts of any kind. A row of hard plastic chairs were crowded together with no space where a family group could speak privately. Moreover, visitors shared this waiting area with hospital equipment: portable x-ray machines, stretchers. Immediately inside the ICU door, just a few feet from where visitors sat was the facility for disposing bedpans. The prevailing odor was a mixture of spray deodorant and human waste. Visitors sometimes waited for hours in this area. There was no evidence that their needs were recognized by medical personnel or that a space inside the hospital had even been prepared for them. I only observed a few times when anyone from inside the unit went outside to speak with a family member. This was how the families were introduced to the hospital experience of their member.

When they returned to the ICU after the patient had been brought up from the emergency room, most of these people had not yet spoken to a nurse, or a doctor. They had received no news other than the brief announcement that a heart attack had occurred, and that the patient was seriously ill, in critical condition.

It was hospital policy not to give a prognosis for at least 24 hours. The family members began their experience as relatives of a critically ill patient highly uncertain of the patient's condition, and, at the same time, completely uninformed about what was being done to the patient inside the ICU.

IV. The Patient's Perspective

The patient in the emergency room and later in the ICU had a different set of experiences than those of his family. The structure of the physical space allowed him different access to information about his condition than his family had, provided more supports for his emotional state and more specific cues for behaviors at the time. William Deane, who participated in the life of a mental ward, commented on the specifics of insiders vs. outsiders access to information:

> This is in no sense a perceptual distortion. It is rather a condition of seeing things through different sets of eyes, which has the effect of making the familiar appear unfamiliar....These are actual perceptual changes, a shift in the way things really look. There is ample evidence that perception of all kinds is affected by continued viewing....[18]

It is appropriate then to compare the experiences of the patients with those of the members of their families, with reference to perceptions, attitudes, and definitions of the situation. The smallness of the room made it relatively easy for patients and staff to observe each other. When patients unwittingly or accidently did something not allowed, staff could notice and correct it. However, not only were patients aware of how staff behaved when treating other patients, but were also able to observe staff in what Goffman has called "backstage behavior."[19] At the nursing station, or at the medication cabinet in the foyer, staff members sometimes stepped out of the nursing role and talked together about topics and events in their personal lives outside of the hospital. Patients who would overhear, were able to get to know staff members as persons. On these occasions, sometimes the nurses talked together about patients they didn't like, or about doctors who appeared to them to be particularly inept or talented. Families did not have this kind of access.

There are two issues to be considered: One has to do with the career of the patient and the family: the relationship between the social structure of the hospital, definitions of the situation, and behavior patterns in response to the changing nature of the illness and therapy. The other concerns the comparison of the perspective of patient and family given the separate, unequal experiences they had, and their consequences for individuals, family groups, and the medical care system charged with patient care responsibility.

For the patient, the experience in the emergency room could be reassuring. Mr. Ambrosio, who earlier had wanted to be taken home against the direct orders of his physician seemed impressed with the way he was treated once he was inside the hospital. Here he did not display any of the non-compliance which had characterized his pre-hospital response to medical advice. He recalled for me his impression of the emergency room:

> When the admitting nurse said to me: '*Get on that table*: she says, *Give me that coat*.' *Immediately*. Doctors K and B came in with their stethoscopes. Meantime the nurse is taking the cardiogram. Another is putting the IV needle in my arm...They wanted my Blue Cross card, that was in my back wallet. I says, here, you can take it. 'No', she says, *you* give it to *her* and *she* will give it to me. They then brought me into x-ray. But all the time I was there the girls noticed that I was sweating profusely. I said, May I have some water? She said, 'I can't do anything without asking Dr. K!' I did and he said why not...Dr. B. explained a few things. He said 'When you go upstairs listen to the nurses. We will be around. Tomorrow don't be afraid if you see about ten or twelve doctors discussing your case.' I said I won't get excited. From the time I got into this place to the time I left, the rapport of the ER was fantastic. (Underlining indicates the patient's emphasis).

For patients who were conscious when they arrived on the ICU the orientation they were given had several common elements. The nurses took an informal and friendly tone. First names were exchanged and there were often attempts at humor. In the course of placing the patient in bed and attaching him to the specialized equipment nurses engaged conscious patients in light conversation about their families, jobs, travels and so on. Nurses would tell the patients about themselves: their marital status, children, a recent vacation trip, etc. The atmosphere was informal; the staff-patient relations were intimate and face-to-face, like a primary group.

For patients, at the point of entry into the ICU, the space in which they were placed seemed chosen to facilitate their learning of important information about their illnesses and the ICU. By comparison, family members in their space seemed specifically to be excluded. Not all of what patients learned turned out to be accurate however. Patients were generally told how long they could expect to remain on the unit but often were kept longer. Families were not given any information until later, and remained in doubt while the patient received positive news. This follows from what a nurse told me about their procedures in receiving new patients: "We tell the family the truth, but are more optimistic with the patients." Giving the patient an estimate of when he would be leaving seemed to be an attempt to control any fear of imminent death, and was thus a mechanism for orderly patient management. Family members were managed, not by information, but by exclusion.

Patients were able to become familiar with the various pieces of equipment around them. When Mr. O'Shea was being attached to his overhead oscilliscope he noticed the red alarm light flash on. He told me that at the time he became very frightened. Immediately the nurse assured him that the alarm went on because the monitor lead had slipped, not because of his condition. Patients could see monitoring screens of others, and in the course of any day observed alarm lights flashing several times. They learned by this that in all but a very few instances the cause was the lead slipping from the body, not an emergency. In contrast, family members usually remained upset by the warning light - and did not have enough experience to take it for granted as patients did. I saw visitors run out of the room crying because something on the screen disturbed them - the light going on, or the beam of light which traces the heart's rhythm "going too fast." Even after Mr. Grasso and a nurse explained to Mrs. Grasso and Anthony, her son, that the red light did not indicate an emergency, they expected the nurses to rush to the patient, and were upset and angry when they did not.

The ICU admission routines appeared to be designed to relieve patients of the fear that they would die, not that they were less than critically ill.[20] In fact, as will be detailed below, much of what was said and done by the staff emphasized the seriousness of the illness. But staff actions seemed designed also to convince the patient that if he cooperated fully by strictly following all instructions given to him he would survive. In this way, staff sought to calm the new patient by convincing him that his death was not imminent; and keep him compliant by impressing him with the notion that his well being was contingent upon following orders. Invariably, the first order to the patient was to remain as immobile as possible. This included no unnecessary movement of body or limbs, no crossing of legs, no reaching. Patients were also told to call the nurses for any needs they had, and to follow all instructions they were given,

Intensive Care Units are expected to make patients' actions highly visible to medical personnel, so that available emergency equipment can be applied rapidly by a specially trained staff in case of emergency. People who have had heart attacks are subject to a condition called "arrhythmia" which is an interruption of the normal electrical conduction of the heart which in some instances can cause death.[21] Most arrhythmias occur within several days of a heart attack. A critical function of the ICU is to detect and treat these events. One medical writer explains:

> Arrhythmias as a group have been responsible for a larger number of in-hospital deaths than any other complications of acute myocardial infarction. The procedure of continuous ECG monitoring in the acute coronary care unit has provided more information with regard to treatment of arrhythmias than for any of the other complications of acute myocardial infarction. Electrocardiographic monitoring in the coronary care unit has also permitted early recognition and active treatment of serious arrhythmias, or prophylactic treatment of minor arrhythmias that are known to lead to

> potentially major, life-threatening arrhythmias. It is in the area of preventing deaths caused by arrhythmias, with the salvage of more patients with otherwise good hearts, that most of the important benefits of the coronary care unit have been realized.[22]

Every person who entered Group Hospital's ICU with a confirmed or even suspected heart attack was officially categorized as "critically ill," and treated accordingly.[23] This seems to be in accordance with standard medical practice, notwithstanding the fact that many who have been admitted will be shown <u>not</u> to have suffered a heart attack. One physician explains:

> This will necessarily lead to many false diagnoses. This is perfectly acceptable. Most coronary care units have up to a 50% misdiagnosis rate. In caring for the patient with acute myocardial infarction we are concerned, in the acute coronary care unit, with a very short but important time span in the clinical spectrum of the patient's disease. We are also concerned with the period of time when the most serious complications (arrhythmias) may arise, even before an accurate diagnosis can be established clinically. Therefore it is wise to assume that all patients admitted for acute coronary care have had an actual myocardial infarction until proved otherwise.[24]

According to the view of the nurses at Group Hospital's ICU, patients who were not worried about their condition were more likely to overstep the narrow boundaries set on their behavior, thus making their illness worse, than were those who exhibited concern. Most heart patients, I was told, begin to feel better after a couple of days rest and medication, and are alert even though they are still considered critical, and at risk for arrythmia.[25] Emergencies brought on by patient overconfidence and resultant overactivity were cited by the nurses as one of the more serious problems of patient care they had to deal with.

As a way of controlling patient behavior, nurses often reminded the patients of the seriousness of their condition. Admonitions not to move in bed were often accompanied by statements like, "When you are critical you can't cross your legs." The "unworried patient" received singular attention. One day, speaking about a new patient (not one of my eight patients) who appeared to the staff to be taking his situation lightly (he was joking about it), and who had already been told of its seriousness, a nurse said to me, "I'd like to tell him what happened to Mr X (a former ICU patient who died on the General Medical Ward from a cardiac arrest) who acted just like he is now." On another occasion, a nurse-supervisor filling in on the ICU was speaking to a patient while making his bed. This patient had been admitted the day before in an unconscious state. He now appeared cheerful and remarked that when he came to the emergency room "for a few chest pains" he never expected to wind up in the ICU. The nurse asked if he remembered what had happened to him the first day on the unit. The man said that he didn't remember. She then wheeled to his bed a defibrillator (used in emergencies to deliver an electric current to the heart to correct a dangerous rhythm). She told him that this had been used to revive him and explained what the machine did. Speaking with me moments afterward, she said that it was good for patients to understand the threat of their illness.

It has been pointed out that, "In the smaller hospital without a physician on hand, the backbone of the coronary care unit is the nurse."[26] On Group Hospital's ICU there were no permanently assigned physicians. Outside of morning medical rounds, doctors appeared on the ICU usually only after being summoned by a nurse. This gave the nursing staff considerable responsibility for noticing the early warning signs of arrhythmias and cardiac arrest, and to respond immediately to treat the failing patient. A great deal of medical care was either carried out directly by nurses or initiated by them. They could not depend on physicians who were in other parts of the hospital.

The fact that patient survival was dependent to a degree on the performance of the nurses appears to have reinforced concern among the staff of the need to severely restrict the patients activity and to define this as a primary part of their duties. Their belief that even cooperative patients could unwittingly precipitate a coronary event was used in explaining the need to never let the patient forget how fragile he was.

Patients knew from many sources that they were not supposed to exert themselves at all until they were otherwise instructed and were to ask the nurses when they needed anything, or wanted to move. Mr. Warren explained to me: "I was very shy up there, and very withdrawn. I waited until the last minute to ask them anything, rather than think I was disturbing them or making a nuisance of myself, you know. Although they hammer it into you: 'Don't do anything for yourself. We are here to help you; just call and we will be there.'" Patients who tried to do small things for themselves and did not depend on the nurses were reprimanded. Mr. Polski said he "caught hell" when he reached for an item on his bedside table. He said that he always tried to "help them" but "they won't let me." Most patients were able to recall an incident where they were corrected and reminded that the staff believed they were in a very fragile state.

Given the small size of the unit, reprimands of patients could be heard throughout the unit. Making a patient's offense public knowledge was an additional social control agent. Even the first offender could be called to order publicly. One newly arrived patient I observed needed to move his bowels shortly after being admitted. The nurse brought the bedpan and told him when he was finished to call to her. A few moments later I heard the patient call the nurse's name in a voice not much louder than one would use speaking normally. At this time the nurse was about twenty feet away from me. I cannot be sure if she did not in fact hear the patient or if she was attempting to teach him an expected patient behavior. Several minutes passed until she looked into the curtained-off area and asked if he was finished. When he said he was, she replied in a loud scolding tone: "I told you to call me when you were finished....You have to yell louder than that here." The patient apologized.

While nurses regularly corrected patients who did too much it was rare to hear a patient be told he was not doing enough. After being on the unit for a few days, patients were instructed to do certain activities for a brief period of time, such as sitting on the side of the bed "dangling," sitting in a bedside chair, moving arms and legs. Later, they would be allowed to wash and shave themselves.

Patients told me, and I observed, that they often tended to do <u>less</u> than they were allowed to. More than once while I was with Mr. Ambrosio, he returned to bed before his allowable time out of bed was up. Once he told me, "I don't want to overdo it, they were great to let me up." Another patient returned to bed because he wanted to "save up" his time for visitors. Mr. Goldberg's approach to activity on the ICU was: "The more rest I get here the quicker I get back to normal at home." When patients did not do as much as they were allowed the nurses did not seem to take notice of this, at least they acted as if they didn't notice. There was one exception I saw involving a man, not among my eight, who refused to wash, shave, or feed himself. His consistent, almost total, inactivity was noticed by staff and one of his nurses refused to perform these services for him. The supervisor of the shift did, however, wash and shave him thereby initiating a brief argument between the nurses. In general, as long as a patient did some part of the activity that was asked of him he could expect not to have any difficulties with the nurses. Doing less than one was allowed to seemed to derive from the high value placed on immobility and dependency. These qualities were held up as prerequisites to getting better. Activity and autonomy, on the other hand, were held up to patients as causes of injury, barriers to recovery. In addition to being suspicious and afraid of activity, patients seemed to draw an inference that doing a little less than allowed could <u>aid</u> the recovery process, The virtues of controlled mobility - which, according to medical sources is an integral component of ICU treatment - were much less visible to patients than were the potential negative results of over activity.[27]

These circumstances fostered the attitude that activity was something to fear. I suspect that without the close proximity of the nurses, some patients would have done less than they actually did do. But because they were watched so closely, and did want to be "good patients", a certain amount of ritual compliance was the result. However, the underlying attitudes, fears and perceptions of patients toward their illnesses which led them to want to do less than the situation actually called for never became exposed as issues of care to be responded to by the medical staff.

The medical equipment on the unit aided nurses in detecting patients' activity. Movement of a patient could dislodge the lead to the monitor causing the alarm light to flash the news to the nurse who would respond by correcting the patient. Activity which caused the heart rate to increase also tripped the warning device. Blood pressure readings, done frequently during the day, could also indicate if the patient had been active. I learned this in a very personal way. Shortly after I interviewed Mr. Polski for the first time on the ICU, a nurse took his blood pressure and announced to me that the interview had caused the patient's pressure to rise. "That's the most activity he's had since he's been here" she said. There were no equivalent aides to identify inactivity.

In contrast to those patients who seemed inclined to less than they were expected to, there were others who did not believe that the ICU's goals and procedures were appropriate "in their own individual case". Three of the men in this study wanted to do more. Staff recommendations seemed to them to be only partially correct, but under the conditions of high visibility they were constrained to behave according to instructions, and thus did not reveal their deviant attitudes.

One of these patients, was considered by the nurses to be a bit overconfident but within the range of "the normal patient." He told me that he did not consider himself to be critically ill, and considered the restrictions placed on him excessive. He said he always tried to "help the nurses", and indicated that by his activity he was trying to show them of his capabilities. Another patient, Mr. O'Shea, said to me on the third day of his ICU stay: "I still can't believe I had a heart attack." After giving me a long explanation of this assessment he shrugged his shoulders and said, "What the hell, I'll just take it easy." The next morning as he was being examined by a group of doctors at medical rounds, a resident remarked that he seemed tense and frightened. The nurse-supervisor reminded the physician that: "You would be worried too if you were in his place." Mr. O'Shea immediately offered that he was not worried and smiled. Later in the day Mr. O'Shea told me that he couldn't understand the resident's statement because "I have no problems and I'm not worried."

Mr. Grasso believed he had a heart attack, but did not think medical science could cure it. He claimed his personality would have to change, and that reducing activities would not prevent another attack.

It is important to note that no patient who seemed to want to do <u>less</u> than was allowed had a prior hospitalization for heart disease, yet each of the three patients who were inclined to do <u>more</u> than was allowed had prior experience with heart disease. This suggests that the novelty of the event might be a key element in the continuance of a self definition as critically ill after severe pain has ceased and the patient begins to feel a return of some vitality.

For patients who did not accept the ICU's critical patient definition, one way of expressing their own self-image was to ask the doctors for permission to begin to move around. Dangling one's feet while sitting on the side of the bed was the first step in a patient's progression of activities, It preceded being allowed to sit out of bed, and being allowed to use the commode rather than the bedpan. Both Mr. O'Shea and Mr. Polski asked the doctors during morning medical rounds for permission to dangle. In both cases permission was granted and the patient-careers were hastened into a new phase. These men took this as evidence that many restrictions placed on them were excessive.

The structure of the ICU constrained all patients to follow orders, and not to "make waves." Patients typically asked few questions about the condition of their health, about the progress of the therapy, or of what to expect when they left the unit. Mr. Asti said, "I tried not to show curiosity," and his characterization of his interaction with medical staff was that he took the "ostrich approach." His bed was closest to the nursing station, perhaps five feet away. Yet he said he engaged in no conversation at all, and even tried not to listen in on their conversation. Mr. Ambrosio said, "Since I have been here I have never asked anyone, - doctor, nurse or resident - what happened, how is the heart, what happened and how is it improving." With medications, he took the same approach, "Here is the medicine, down the hatch... I never would say what is the green pill, or the yellow pill, or the blue pill, whatever it was. I never asked any questions." He summed up his philosophy this way: "My whole concept since the day I came in here was: Don't worry. Let your mind go blank."

A similar approach was expressed by another patient, Mr. Goldberg. This was a man in his early sixties who had complained of chest pains for weeks before his attack. He then was given nitroglycerine by his physician, a fact which Mr. and Mrs. Goldberg used in arguing after the attack that if their family physician had hospitalized him sooner, the coronary might have been prevented. He told me he asked few questions in the ICU because, "If they want me to know something important, they'll tell me." However, he also revealed that he was frightened of what he might learn from questioning staff members. He said, "If you question too much, he'll make a slip he doesn't mean." Fear of having bad news came through in listening to other patients. For example, Mr. Ambrosio told me: "If you ask questions, they're under pressure. They don't want to be in a position of saying 101% that you will be alive."

Other patients reported not inquiring about the details of their treatment because they "knew" they wouldn't be told. Moreover, they seemed to indicate that they had no right to this information. Mr. O'Shea said it would be "unethical" for a staff person to even tell him what his blood pressure reading was. Mr. Grasso similarly offered that it was the doctor's prerogative whether to reveal information to him or not.

Questioning was, in a number of ways discouraged. On morning medical rounds the medical director led a review and discussion of each patient's progress with eight to ten medical residents and the nurses. This occurred at the bedside of each patient. In effect, the patient's present state of health was analyzed: his latest ECG's were analyzed for changes in pattern, lab reports were reviewed. The discussion was highly technical with no effort made to translate into lay terms for the patient. Without having knowledge of the technical language, patients could not participate during rounds. Patients were told they "should not be concerned" with the proceedings, and the way doctors explained this event to the patients implied that rounds had little relevance to them. Mr. O'Shea told me he was forewarned in the emergency room that in the morning a group of doctors would examine him but "Don't worry about it, it involves medical stuff. It's academic so don't let it perturb you." New patients were almost always told by the medical director that what was being discussed was "for the doctors," and they "should not be disturbed," by the discussion or by the fact that ten doctors were examining them. What he seemed to be implying was: "Your condition is not your concern." Patients on the unit for several days, were also sometimes reminded not to take too great an interest in rounds. One morning after Mr. Goldberg's care had been discussed at his bedside, the medical director told him "not to mind" what had just transpired. Later, Mr. Goldberg told me he should have replied that he was "listening to further my medical studies" which was a rather incisive bit of humor. I asked him what he had heard that morning. He replied, "technical jargon." Did he ask any question at the time? "No."

Generally, no questions were asked of the patient at rounds that allowed any expression of his opinions or feelings. Questions asked required only a yes or no answer, as when the patient is asked: "Do you get pain when I touch you here?" The few patients I observed who did expand statements of how they felt, or who tried to inquire why they felt pain or continuing discomfort were either given very brief responses to their statements or were interrupted by the medical director who told the resident to explain to the group the details of the case.

Even the positioning of the staff vis-a-vis the patient constrained against his participating in discussions of his own case. During the proceedings, the medical director stood behind each patient and spoke out to the residents and nurses who were gathered around the body - sometimes looking at long EKG print outs which were strewn across the patient's body which was used like a table for lab reports, charts an EKG print outs. To address the medical director, the patient would have had to turn around, a movement which was not permitted.

Before the group moved to the next patient, the director usually - although not always - made a statement to the patient that he "was doing fine," or "the best thing you can do for yourself now is take it easy." I never heard him tell a patient he was not doing well. Usually something positive was said. Patients acted passive; by far the most frequent statements made by patients during rounds were in response to humorous remarks to them from the medical staff. They seemed pleased when doctors joked with them.

V. Events Preceding Transferring the Patient to the General Medical Ward.

Another factor which may have had a bearing on why patients did not raise issues or questions they had about their illness, their progress, or their future care was the time orientation of the unit which emphasized the present. The unit had only two small windows and these gave little natural light. The room, dim at all times, made it appear as if time were not moving. Patients often remarked that they were unaware of the time or that they were surprised when they found out the time of day.

As the time of transfer to the General Medical Ward approached, the condition of the patient was expected by the staff to have changed for the better. On the ward he would not be monitored electronically, and nurses would be less available to observe him closely. Also, a patient would be given more personal choice over his own movements. On the ICU. there were no organized procedures to prepare a patient for this change. There was little discussion of what was in store in the future. There were few opportunities for patients to anticipate the future and raise questions about the state of their health.

In many ways, patients about to be transferred off the unit were treated just as they had been as newly arrived patients. Restrictions on activity remained severe up until transfer. All patients new and old, spent most of the day in bed. Time out of bed sitting in a chair was brief, walking was almost non-existent. Even in cases when patients were allowed to sit out of bed at will, they generally spent most of the time in bed. All patients, new or old, were attached to the monitor. Schedules were the same, as were visiting regulations. To the end, the emphasis was on what the patient should <u>not</u> do.

Patients had little advance warning as to the time of their transfer off of the ICU to the General Medical Ward. Even a patient who felt better and who had been allowed to sit out of bed could not be sure when he would leave. Mr. Warren told me: "They'd rather keep you here as long as they can, because you have all them gadgets on you and they can keep better tabs on you." I asked him to tell me how he learned he was leaving the unit:

> Dr. F. checked me over. He said you sound pretty good, we're going to try to get you down there as soon as possible. I didn't know whether that meant that morning, in the afternoon or the next day. But then the nurse came over and she took the leads off my chest. Once she had done that...I said 'Am I going down?' She said yes... She wanted a urine specimen and she came back after an hour. She said, 'Not yet?' I said, no, because I wasn't in a rush and I wanted to make sure that I had to go. She said: 'Well you can go downstairs after you give me a specimen.' So I says: 'Well, I didn't know <u>that</u>' (his emphasis). With that I drew the curtains and gave her the specimen.

Mr. Asti was told during the morning rounds that he would be leaving the unit. Less than three hours later he left.

As previously stated, patients were given an estimate of their probable length of stay soon after their admission into the ICU. But they were also told at that time, and if they asked again, that the exact timing of the transfer depended upon a bed being available for them on the General Medical Ward. So when they were told they were leaving, it came as a surprise, and they had little time to make the adjustment.

The nurses also told me that a patient's stay could be extended on the ICU if several ICU beds were empty. Their perception was that the residents in emergency room lowered the standards for ICU admission when several beds were available. The nurses said they would rather keep patients on the ICU to get "the benefit of the monitor" than care for patients not critically ill to begin with.

After patients are told they would be transferred, they received instructions which were similar to those they had been receiving all along: do not be active, be cautious. The statement - "Take it easy down there; no running around. We don't want to see you back up here" - was repeated with slight variation each time a patient left. Mr. Ambrosio said he was told: "Some people... they think they can go back and feel like Superman. But that is where they make their mistake."

Until they leave the ICU, patients were constantly reminded of their fragile physical conditions. They were continually treated by means which emphasized their dependency on the nurses and the life support technology. Sign which indicated progress were few in comparison with those indicating stasis.

In a real sense, it was the structure of the setting which determined the patients' experiences, access to information, and defined their status on the ICU, not their objective physical conditions. The ICU was organized to deal with critically ill patients, and the routines, procedures, and staff orientations were geared to this purpose. ICU staff nurses felt accountable for patients once they left the unit. Deaths of patients on the General Medical Ward who had recently been cared for on the ICU were very much a matter of concern to the ICU nurses, especially if deaths occurred suddenly and unexpectedly. Staff considered these post-ICU deaths to be mainly the result of patients' lack of judgement on the ward, and assumed they had been overactive, - something their ICU experience should have taught them to avoid. When staff discussed a post-ICU death, they usually reviewed how the patient had behaved on the unit. Whether he had shown signs of overconfidence. They recalled how often the patient had to be reminded to take his illness seriously. If a patient who had shown proper concern suddenly died, this seemed to remind the nurses of the inherent uncertainty of heart attacks.

This was an area of strain for the nurses: even after a patient left the unit and his actions were no longer under their control, staff still felt responsible for his survival.

When a patient had to be returned to the unit following an episode of symptom reoccurance, the critical care methods were quickly reapplied. After Mr. O'Shea who had been quite active on the ward fainted, he was returned to the ICU "for precautionary measures." Tests showed that he did not suffer any additional heart injury. His blood pressure was low, however, and he was placed on medication. For about a week he was back in his old bed on the ICU, being treated much like he had been when he was initially admitted for his heart attack. Again, he was indistinguishable from any newly arrived patient. After staff felt that he was able to return to the ward, Mr. O'Shea was still kept on the ICU. The nurses told me that they could keep better tabs on him to make absolutely sure he had no reoccurrance of fainting. As the days passed, they began to allow Mr. O'Shea privileges other patients did not have. They let him walk more, and even allowed him to visit a friend who was on the unit. In this way they seemed to justify his presence on the unit. One nurse said: "He is doing as much as he would be on the ward."

The experience had a profound effect on Mr. O'Shea. He believed his condition had taken a drastic turn for the worse. He became despondent and displayed none of the joviality or optimism which had come through in our earlier conversations. He searched for clues to confirm his pessimism. For example, he recalled that he was told upon admission that he had suffered an acute myocardial infarction. Now the term "acute" took on great meaning. I advised him to ask for an explanation of the term and suggested that it might not be as extreme as it appeared to him. He refused to ask. When a doctor told him that men his age often had low blood pressure, Mr. O'Shea told me that he was afraid that the doctor was not aware how old he really was because "I have a young looking face." At home, three months later, Mr. O'Shea exhibited similar fears and doubts which resulted in a great reluctance to reengage normal social roles.

VI. Comparison of Patient and Family Perspectives

During the length of the ICU stay, the families' access to staff and to information about their sick members remained limited. Several wives sought out their family physicians as a source of information. In no case was this successful, according to what these spouses told me. Mrs. Grasso, for example, recalled: "My family doctor...said to Adam, 'why doesn't your wife call me during visiting hours?' He must have mentioned that my wife is trying to get you...Well, I thought I did call during visiting hours." Mrs. Asti's experience was similar. She called Dr. Ay and was told by his secretary that he was out to lunch and that she should call back at 2:30. When she did call back, Mrs. Asti was told that the doctor had gone for the day. She asked me if I thought she had gotten "a runaround." I said that I really didn't know but maybe there was some confusion over the phone and that the secretary didn't understand her. Mrs. Asti responded that probably Dr. Ay gets too many phone calls each day to cope with and that he gives out false information to reduce some of them. She did not call him back.

After failing in their initial attempts to contact their family physicians, no second ones were made. We will discuss the factors which seemed to have led the patients and the families not to perceive the family physician as a source of assistance in the illness in the next chapter.

The attending physicians, employees of the Medical Group, who examined patients each day did their work prior to the first family visiting session. Consequently, they were either in other areas of the hospital, or at one of the Group Centers seeing ambulatory patients when the families arrived. As mentioned, residents were more often than not away from the ICU, or were there because of some urgent medical need. Chances of encountering a physician on the ICU were, for the families, not good. One spouse who tried to seek out the attending physician told me during my first interview with her:

> Dr. K., who is the resident doctor there is a wonderful doctor and a wonderful person. I said to him: 'What has happened to my husband? What is the diagnosis? What must I do after he comes home?' Dr. K. said: 'You call Dr. Ay (the attending physician assigned to her husband's case) and make an appointment and he will stay and sit with you for one hour and tell you everything, what to do, what has happened. Have him have it in writing.' But forget it. When I called, his secretary, Mrs. G., said he has no time to see the family of the patient. He is too busy.

The other spouses did not attempt to inquire about the details of the course of illness, the treatment, or the next steps in the treatment:

E.S.: When you were visiting your husband this week (on the ICU) have you spoken to any of the doctors at all?

Mrs. Polski: No.

E.S.: Have you wanted to?

Mrs. Polski: They told my husband, you know, that the x-rays had shown he has a massive heart block. They told him and he just told me, and I didn't feel that I had to go to the doctors. He wasn't there anyway or to the nurses because they gave all the information to my husband and he told me, so what else could I do, right?

A few moments later I asked what it was her husband had been told by the staff. She replied, "He don't know. They don't tell him anything. So we have to wait and see, right?"

Mrs. Asti always responded "yes" whenever I asked if she had any questions. Yet she could never specify what these were, and never spoke to any physician until the day her husband left the ICU. One day, after I again inquired about her questions and of her desire to speak to a physician, she said in a highly frustrated manner, "I don't know about the heart. I probably wouldn't understand if they told me." Did she want to speak to a doctor? "Yes," was her reply. She seemed to want the experts to take the initiative and explain the whole matter to her.

In a number of ways, family members' reluctance to inquire about the treatment and the progress of the patient stemmed from similar perceptions patients had. Mrs. O'Shea, like her husband, told me it would be unethical for a staff member to reveal information to her. To others, the nurses seemed "too busy", and should not be interrupted. One wife suggested that if staff members were "bothered" by questions, they would in some way retaliate against the patient or the family. She said that although she was normally "nosey" she refrained from pursuing answers to the questions she had because "I need them now."

In an attempt to elicit information from the staff, some family members took what they considered to be deviant paths. As Roth[29] has pointed out in his study of TB patients and their families, this is a common coping devise when staff close ranks against giving out information. Mrs. Grasso claimed she "sneaked a look" at her husband's chart, and on the basis of what she learned felt relieved that his blood pressure was within normal limits. Mrs. O'Shea also "looked over her shoulder" to see what was written in the chart. This kind of activity is reminiscent of how some wives had attempted to gain access in the emergency room.

The little that the family members were told emphasized the seriousness of the illness. What they saw from their vantage point outside the unit, and in the brief periods on the inside reinforced this perspective.

Their vantage point contained very few symbols of improving health. Family members were frightened by the unit and sometimes reduced their time spent there. Mrs. Warren said it upset her because she was not the type to be near "the deathly sick." Also, she said she was "afraid of blood." Mrs. Asti "went crazy" when the red alarm light went on the monitor as did many other family members. Susan Asti had to force herself to come into the unit and didn't stay long. Mrs. Ambrosio ran out of the unit and broke down crying because the pattern of the monitor seemed "too fast." (I learned later that actually the monitor's speed was normal).

The waiting family members seemed to be in a constant state of anxiety about the fate of their loved ones, and the tone of the ICU exacerbated this:

> E.S.: In other words, you saw the ICU as a frightening place?
>
> Mrs. Grasso: Well, the first time yes. Of course even up to now I don't like watching that scope. I was telling you about the light flashing and all that. There's a lot of things going on there too, there are emergencies. That makes you (pause)...In fact, the first day he went downstairs Anthony and I were leaving the hospital. As we were getting out of the elevator a nurse came darting into the elevator with two big needles like I've never seen anything like it taped to a cart or something. She said: 'Please don't move!' She made a motion to push us back into the elevator. She had an emergency on the sixth floor. That was frightening in itself. Knowing he was on the third was a big relief - that it wasn't your own. You know how you feel. You don't want to see anyone suffer. But it wasn't your own.

In contrast, patients were able to utilize the emergencies and the deteriorating conditions of other patients around them as testimony of their own <u>relative</u> well being. Other investigators of heart attack patients have made similar observations. McEwen has recently reported:

> The staff are by no means the only significant others. As patients recover, they come to spend an increasing proportion of their time in observation of and interaction with fellow patients. There were many indications that for some patients this period markedly affects the way they come to see their own illness sometimes very positively. (my emphasis)[28]

Mr. Warren compared himself favorably with a nearby patient. He explained how a patient could develop a relative sense of optimism:

> I was scared to death... So outside of worrying for the first day especially, because the pain stayed with me from the time I got in there until about 7 o'clock at night when they gave me the demoral that didn't agree with me. So I wondered when is this pain going to leave me, you know. So once I got over the pain lessening and I felt good I had no qualms, I didn't worry too much. I seen others around me that were worse off than me, like that Joe, he got to stay 4 or 5 weeks.

When emergencies did occur inside the unit or when several patients turned for the worse at once, the nurses had to pay less attention to the more stable patients. One evening in particular, several of my study patients received evidence that their own needs were far less acute than those of others. Two patients suddenly declined - and several doctors joined the nurses in an attempt to save them. Three of my patients, all of whom had been on the unit for several days, were awake to witness the events. By morning, the unit was still in a state of agitation. When certain routines which my patients had come to expect did not occur, they asked for them. The nurses indicated that it was selfish of them to expect to be attended to when others had much greater needs. By events like these, patients began to differentiate themselves from the "serious" ones.

The way that I saw family members behave while on the unit gave evidence that they continued to hold a highly fearful and conservative perspective right up to the transfer off of the unit. <u>Even the most fearful patient appeared more confident than his family</u>. When spouses and children noticed the patients becoming gradually more active they tended to <u>discourage</u> them from exercising the small amount of freedom the unit allowed. When Mrs. O'Shea visited her husband in the ICU she urged him to return to bed if he was seated in his chair. So did other wives and some children and relatives. They responded the same way to other things the patients did. When Mr. Ambrosio started to put on his socks in the ICU his wife tried to stop him. He was permitted out of bed, he was allowed to put on his socks. Some families even tried to discourage the patient from talking because they still thought it was too strenuous. I observed Mr. and Mrs. Goldberg arguing about whether Mr. Goldberg could eat all of the food and use all of the condiments on his tray. She succeeded in reducing his use of a substance on his tray she called salt. Another patient was fed by a relative after being told he <u>could</u> and <u>should</u> feed himself.

Mrs. Ambrosio told me, "When I go, I say, 'when you have to use the commode you call' (an aide). 'Don't tell me, I <u>know</u>' (he replied)...like everyday now I say, 'Now Dr. B. told me, and he told you you must not exert yourself, don't worry be calm, and take it easy. It will take a little time and you'll be well.'" It was difficult for families to accept the freedoms of mobility the patients gradually acquired since only immobility seemed to be indicated from their standpoint.

This suggests an unintended negative consequence of keeping the family outside of the treatment setting where they are unable to clearly apprehend the nature, content or process of care. When the family members are finally permitted into the setting, their lack of understanding, together with their desire to help leads them to unwittingly work against the treatment plan. The assumption that keeping the family away from the patient will prevent interference with the staff's work, and rule out the danger of having the patient upset or excited by interacting with his close kin is not supported here. It seems that had the family members been acclimated to the ICU they would have been less of an interference.

When the time of the patients' transfer arrived, the families seemed not to welcome the change. They did not consider it, as most patients did, as a sign of health improvement, or a positive step. They still felt the patients needed ICU care. Shortly after the actual transfer, I asked each family member how he/she would have felt if because of a shortage of beds on the ward the patient had to remain on the ICU. Mrs. Warren gave a typical response: "Well, I think it would have been better. I mean to stay on the safe side, although the doctor said no, that he was able to go down, because of the care that he was getting.. They're very nice, you know. They were checking his blood pressure a couple times a day... they were taking his blood tests a couple times a day." Mrs. Grasso said: "I would feel it was good because they're right there for everything and there would be a lot more rest added to it."

Here we see another consequence of the family's "outsider" status: a discrepancy developed between the expectations of the family and the decision made by the medical staff to transfer the patient off the ICU. From the perspective of the family, the patient still needed intensive care "to stay on the safe side." Apparently, the considerations which led the medical staff to judge the patient fit to move to a new phase of care were not obvious to the family. The barriers which had kept the family physically separated from patient and staff produced a widening conceptual gulf between the family and the staff. Moreover, at the time of transfer from the ICU, the family and the patient had formed significantly different perspectives on the improvement that had taken place since hospital admission, and on the requirements for getting well.

In keeping with their perception of the patients as highly fragile and easily susceptible to relapse if disturbed, family members generally refrained from discussing the illness or treatment with the patient. The general approach was articulated by Mrs. Stein: "We didn't talk much to him while he was there, and likewise he to us. Because it was too much. We didn't want to tax him too much. We felt it would be better that he slept and rested."

Mrs. Grasso was told by her husband that he had developed a blood clot, called an embolism, which was being treated by medication. She avoided discussing this with him, however. "I didn't want to press it. I didn't want to speak about it too much."

Given the brevity of the allowable visiting time, and the limitations on numbers of visitors permitted at the bedside, each family member had few opportunities to assess that state of the patients' definition of the situation.

Until the heart attack victims actually entered the hospital, they were not treated like coronary patients, in spite of their symptoms, including changes on the electrocardiogram. The response of the medical care system was specific to the social setting, not to the actual state of illness.

This continued through the ICU experience. Even moments before the transfer, the patient, now at considerably less risk than he had been at admission, was treated much the same as a newly arrived coronary patient.

The Intensive Care Unit is not only a setting for the care of the seriously ill, but it is also a point of entry into a system of health care. The experiences the patients and their families had suggests that these two functions are not easily blended. Being on the ICU constrained against anticipating the next level of care, or appreciating what changes had taken place in health status. The day-to-day routines minimized the patients' awareness of their own physical integrity, discouraged questioning or anticipating problems to be faced once the rigid restraints against mobility were lifted. These same structural factors also prevented the family of the patient from expression and staff from noticing and/or dealing with fears, uncertainties, and misunderstandings. In the following chapter, we will deal with the consequences of such lack of socialization into the health care system.

The structure of the setting kept families at a great social distance from patients and staff throughout. It is not surprising that discrepant perspectives developed. We shall see if this gap closes on the ward where chances for interaction are increased. But we have seen that the family was excluded from any meaningful participation in the unit, and was unable to share the experience with the patient. Their actions on the unit indicate that they were misinformed about the care, and in several instances attempted to interfere with it.

Strauss[30] has suggested that in order to understand the social factors underlying a particular mode of interaction, one must first assess what is at stake for the parties involved. The role of the ICU nurse contained limited options for transcending the instrumental goals of providing critical care. By training, and by virtue of the heavy responsibilities placed on her for patient survival, the nurse directed all of her attention to preventing those behaviors which <u>could</u> lead to potential injury. The possibility that the impression made on patients and families could cause readjustment problems later at home was perceived as outside her purview.

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Chapter III

The General Medical Ward and Perspectives Toward Recovery

I. The Patients' View

Patients went directly to the General Medical Ward from the ICU. In this new care setting, the recovering heart patients were placed side by side with those who either had been on the ICU earlier, or who had other illnesses. The physical conditions of the roommates varied considerably. Some newly arrived post-ICU patients were placed in rooms with men considered by the nurses to be dying. In other cases, their roommates were active and about to go home.

As soon as the patients arrived in the ward, they become virtually indistinguishable from other non-coronary patients. There were no oscilliscopes monitoring the heart rate, nor nurses constantly observing them. All were given permission to remain out of bed, and could use the bedside commode or walk to the toilet if there was one inside the room. Their schedule of meals and other routines were identical with non-coronary patients.

Considering the restraints these patients had been under up to the moment of their transfer, the situation they now found themselves in represented a considerable shift in emphasis. Mr. Asti recalled that when he arrived in his room on the ward the only instructions he received were "not to leave the room, don't wander." He suddenly had choices he didn't have before;

just as when he arrived on the ICU his options had been suddenly and drastically reduced. Each setting had its own structural constraints which the patient had to adjust to.

To some patients the lifting of restraints posed a dilemma. Their self definition as seriously ill patients which was fostered and nurtured in the ICU seemed incompatible with the less restrictive climate on the ward, and threatened their sense of security. Patients who felt they still needed to have medical expertise in close proximity to themselves as was the case moments earlier were suddenly faced with the prospect that they "were now on their own."

One typical mode of patient adaptation to the General Medical Ward was to continue behaving as if one were still on the ICU. In spite of the greater opportunities for autonomy and freedom of movement some patients remained committed to the values and norms of the ICU. I asked Mr. Asti, who arrived on the ward at about 11:00 A.M., when he first met any of the medical staff. He recalled that a "nurses' aide" came in during the afternoon with medication, and at about four a nurse gave him an injection. Even though he was told only not to wander out of the room, he did not walk in the room at all, he continued to sit next to his bed or was in the bed all day. He remained passive and inactive, in accordance with his self image as a seriously ill patient.

Mr. Ambrosio is a case example of a patient committed to his ICU perspective who attempted to impose his own definition onto the staff. I was present during his first interaction with a ward nurse. He had been waiting anxiously for one of the medical staff to arrive, and was disturbed that this did not occur immediately. When the nurse came to the bedside she asked his name and seemed to check it against her notes. She asked if he had been given instructions from his physician, and when Mr. Ambrosio indicated that he had, she began to back away toward the door still jotting notes. Mr. Ambrosio began to speak rapidly, saying that he was told on the ICU to restrict his movements to the area between his bed and the near wall. He moved to the end of his bed and drew an imaginary boundary line with his finger. He seemed to be trying to slow the nurse's departure, to inform her of all the instructions he had been given -- not to overtire himself, to walk a little but sit or go to bed when he felt he was tiring. She didn't reply verbally, but nodded her head and left the room. Within a half hour an aide brought him his lunch. She placed the tray several feet from his bed, beyond the boundary line he had earlier drawn. He would not retrieve it. Later, when a nurse noticed the tray she asked Mr. Ambrosio why he had not eaten. He told her that his doctor did not allow him to walk the distance required to get the tray. Later he told me he was glad this had happened because it gave him the opportunity to convey to the nurses what his regimen was supposed to be.

For patients like Mr. Asti and Mr. Ambrosio the sudden shift in the orientation of the medical staff came unexpectedly.

They behaved in a manner which suggests that they were frightened of no longer being under the scrutiny of medical experts, that they were not confident of their ability to act on their own. Although the structure of the General Medical Ward allowed patients the freedom to increase their mobility and expand their level of activity, the manner in which patients were suddenly moved there from a setting which demanded passivity and caution served to actually increase their psychological dependency. In the absence of medical personnel insisting on inactivity and dependency, some patients demanded this of themselves as a defense against the dangers of over confidence which had been internalized during their ICU stay. At least at the outset, the General Medical Ward routines had, for some patients, an effect which was the opposite of that which was intended.

Not all patients, however, were disturbed by the absence of restrictions and staff to enforce them. To some, the ward provided freedom of movement they wanted but could not obtain on the ICU. Mr. Polski immediately left his room and walked through the corridors, even though he too was told "not to wander" from his room. Mr. O'Shea did the same. Both believed that the hospital's routines were generally too harsh for their own cases, and took advantage of the relative lack of nursing contact on the ward to expand their activities.

Regardless of the definition a patient held of his condition as he entered the ward, he could find evidence to reinforce his perspective. This selective perception occurred within the wide range of images of illness the patient had to choose from. Those who on the ICU wanted to do less than they were told, continued to perceive dangers in activity. Mr. Asti, for example, told me that seeing one of his active roommates suffer a "heart injury" convinced him to be cautious and not join the others who, according to him, were often very mobile. In almost every conversation I had with Mr. Goldberg he brought up the death on the ward of a young man who previously had refused to obey doctors orders and walked the halls, even smoked in the toilet. He said he learned from this to "follow what my doctor says." Mr. Goldberg's interpretation was to restrict himself to very little activity throughout his hospital stay. Based upon what he told me, he was less active than he was advised to be. He interpreted this as "being cautious."

The patients acted according to a definition of the situation which was derived from the ICU experience. This colored their interpretations of instructions given to them by physicians and nurses. The prescriptions given by staff about how active patients should be were open-ended and did not attempt to precisely outline how much a patient should walk, sit, or nap. They counseled discretion. Patients were told they should walk around the room, and later outside the room, but not to overdo it, and to return to a chair or to bed when they felt tired. The chief cardiologist told me that "patients tell us how much they can do," indicating that there were no hard and fast rules physicians could apply in rehabilitating the heart patient. The goal was to have the patient himself learn to moderate his activity according to the limits of his strength and vitality. Of course, the self-initiated activities were to be undertaken within the framework of general guidelines set by the physician.

But there was little way the medical staff had of knowing whether a patient was doing enough, too much or too little. The general advice was recorded on each patient's chart, but the high nurse-patient ratio precluded close observation of what actually occurred. An additional factor was the ward nurses dealt with a variety of kinds of illness, and did not have any specialized knowledge or training in the care of the coronary patient as their colleagues on the ICU had. Unless an open flagrant violation of rules occurred, the ward nurses seemed not to notice small signs indicating that patients were misinformed, frightened, over confident or confused about the proper medical regimen, or if they rejected it all or in part.

Left to decide on their own the pace of daily living on the ward, a number of patients took a highly conservative approach to their activities right up to the time of their discharge. They never seemed to find a balance between caution and confidence but preferred to "stay on the safe side." Mr. Warren told me shortly before he left the hospital that he had the "freedom of the room." I asked how active he actually was. He replied:

> Mostly walking from here to the bathroom and back to the chair. You don't like pacing the floor or anything. I've either been in the chair or sitting like this in the bed. I'm trying to take it as easy as I can.

Mr. Asti took a very similar approach. He had exhibited a considerable amount of fear of activity since he entered the hospital. By the time of his discharge, these fears seemed to be unabated:

> E.S.: (Interviewer) Did (the doctor's) telling you that you are leaving and here are the instructions make you a little more active?
>
> Mr. Asti: No, outside of walking across the room to get out of the way of people working, that was all.
>
> E.S.: And was it different the previous day?
>
> Mr. Asti: No
>
> E.S.: Or the day before that?
>
> Mr. Asti: No

On the other hand, some patients used what they saw or experienced to justify engaging in desired behavior, some of which was clearly in violation of hospital rules. Mr. Stein, for example, learned that not all staff members would express serious opposition to patients' smoking in the hospital. He was aware that other patients used the toilets in the hall to smoke and that their behavior was not exposed. He also learned that there were people who would supply patients with cigarettes -- visitors, even some aides. He told me that while he was waiting to be given tests in the basement lab area he asked a staff member for a puff on this person's cigarette and this was granted.

He began to regularly join the other smokers in the bathrooms in the hall. He even smoked in his own room, and claimed that some nurses detected this but said nothing. He did receive a harsh criticism from a nurse on two occasions, and stopped smoking in the room when she was on duty. Being detected smoking by a nurse, however, did not result in any more disciplinary action than being told to stop. No one ever came to Mr. Stein to discuss his smoking even though he was detected. His own belief was that several cigarettes a day would do him no harm -- and could point to medical staff who by their tolerance of his behavior seemed to support his viewpoint. By the time he left the hospital, however, he said he had "failed completely" to hold his smoking to only a few cigarettes a day.

Mr. Polski told me that the attention he received from nurses had been diminishing since he arrived on the ward. For example, he said, "Now that my blood pressure is normal, they don't take it half as much as they used to." Then he related a story about a nurse who came into the room to take patients' temperatures. She is alleged to have said: "Oh, you don't need it" and with a wave of her hand she dismissed his need for this procedure.

While Mr. Polski's response was directed at expanding his range of activities, it had several elements in common with those whose illness definitions inclined them toward minimizing activity. He interpreted the ward routines with the perspective he gained on the ICU. The structure of the ward setting allowed him to reinforce these beliefs, and his low visibility to staff allowed him to behave in accordance with his perspective.[1] Thus, by the end of the hospitalization period his own interpretation of the nature of his illness, and of what should be done about it was firmly established. It was also quite at odds with what the staff expected of him. Mr. Polski saw his future in terms of resuming completely his former lifestyle. He perceived the ward routines as being incompatible with this expectation. As he had earlier, in the final days of his ICU stay, he made the judgement that the instructions given him were cautionary but not essential to his well being. He told me: "Lying here is not going to get me any stronger. That's why I try to do more every day." He began a daily program of exercise which he knew to be outside of the general limits set by his physician. First he tested himself regularly to learn how much strain he could tolerate by lifting heavy objects around the ward, even though he did once feel a stab of chest pain. He started by lifting chairs and pushing heavy doors. He walked up and down the halls before he was even permitted out of the room. When I asked him if he thought this was advisable in his condition he replied that if he allowed himself to remain inactive he would not be strong enough later when he wanted to resume building his country home. To put his strengthening program into effect he learned when the nurses were changing shifts and their attention would be diverted.

We might examine the actions of these eight patients against the theoretical framework of the doctor-patient relationship suggested by Szasz and Hollender.[2] In their terms, the recovery from an illness like heart attack would involve a progression of stages of the doctor-patient relationship. The first stage, Activity-Passivity, might characterize the most acute phase of the illness and be appropriate during ICU care. Here the orientation is one in which the patient is more or less completely helpless and the physician <u>does</u> something to him.

Once the patient is capable of following instructions and exercising some judgement, as the men on the General Medical Ward were expected to do, a new stage of the doctor-patient relationship-Guidance-Cooperation - is supposed to replace Activity-Passivity. As Szasz and Hollender explain, in this approach the patient is expected to look up to his physician and obey him. While the patient is still very much dependent on medical advice, the success of the therapy requires the patient to adopt the physician's goals as his own, and <u>act</u> on them. As Lorber,[3] and Duff and Hollingshead[4] point out, often the motivation for the hospitalized patient to comply with physician expectation is supplied by the implicit threat of punishment if he refuses to follow orders. Under Guidance-Cooperation, the patient might comply with certain directions because the doctor so <u>orders</u> and the staff enforces them - not because the patient himself understands and accepts the need for such a course of action. Another reason why the hospitalized heart patient may cooperate with the prescribed regimen may be because he feels reassured that the presence of medical experts will protect him from harm which may accompany his increased activity. Without such reassurance, the fearful patient might incline toward doing less than ordered.

Patient care routines on the General Medical Ward suggest that the staff took for granted that the Guidance-Cooperation mode of doctor-patient relationship was operative. Yet, as we have seen, for some patients the change in their care to less intense, frequent and controlling staff involvement only more firmly imbedded them in a passive-dependent orientation. Other patients responded to the ward routines by becoming more self-initiated, and thus more active, than the staff expected. The organization of care at Group Hospital operated under the assumption that Activity-Passivity would prevail on the ICU and Guidance-Cooperation on the ward. The staff behaved according to these organizational expectations. The patients, however, were led by these same organizational constraints to either continue their dependency, or to move beyond the expected level of self sufficiency.

The fact that the patients saw their attending physicians each morning did little to expose patients' deviant attitudes and behavior to the staff, or clarify the intentions of the physicians with regard to the purpose or content of the regimen.

Patients gave information to physicians about the content of their daily activities in the same general terms as the physicians had used in describing the regimen. A patient might say, "I feel OK, I do some walking each day and when I get tired I sit down," and it would apply to a patient doing very little, just as well as to a patient doing quite a bit. They were not encouraged to elaborate. Patients like Goldberg and Asti who remained very sedentary on the ward because they were fearful of reinjury, could answer affirmatively when asked if they were getting on their feet. They had occasion to be active -- walking to the bathroom, moving while the room was being cleaned, and other times when they were <u>forced</u> to move. Since the doctors did not specify the amount of exercise the men should take, or to what degree they should be increasing their activities, the men could believe they were, in general terms, compliant and could present themselves to their doctors as such. This general answer always seemed to satisfy the doctors who did not demand to know specifically what the patients had done or their reasoning behind it. There was never any testing of patients' knowledge of the regimen, nor did it seem that questions from patients were encouraged except for those of the most basic type. (i.e., Can I use the toilet in the hall?) Questions put to patients by doctors remained technical. (Where did you feel discomfort?) Patients were not encouraged to give more than very brief answers, often of the yes or no type.

Patients like Mr. Polski and Mr. O'Shea who knew they were going beyond the bounds set by their physicians seemed able to convey that they were doing less than they actually were and to hide their activity. Mr. Polski, who did not reveal to staff his activity program, said his doctor told him, "If all my patients had your attitude, my job would be half done." Mr. Polski was cheerful when his doctor came, told him he felt good, and indicated he was accepting of the hospital routine. Indeed, since he had figured out how to "beat the system" he was cheerful and had no complaints. Mr. O'Shea was not reluctant to misinform staff. When a nurse asked if his doctor allowed him to be out of bed one morning after he had experienced pain the night before, he replied yes. When the nurse left, he turned to me and said he actually had been told to remain in bed for the day.

One wonders about the lack of probing questions asked by the staff to determine if patients understood the recovery process. Patients were certainly not revealing this information on their own. One must realize that the physicians assigned to patients at Group Hospitals would not be following up the case later during the home recovery period. Their focus was on the immediate medical situation, not on attitudes and perceptions which would have a bearing on the way patients responded to the medical regimen later on when they were no longer their responsibility. As long as there was no indication of any exacerbation of symptoms neither patients nor medical staff seemed to raise questions about compliance. If x-rays, electrocardiograms, and the other medical tests were within normal limits, and the patients experienced no chest pain, everyone seemed satisfied. The patients were content to continue behaving in the future as they had in the recent past. For the sedentary ones this meant that their highly cautious response had been responsible for their present state of relative well-being, and were not motivated to change a strategy which seemed to work for them. On the other hand, active patients looked on their present progress as confirmation that their self-initiated activities were not harmful and might even have helped.

Only one patient, Mr. O'Shea, was returned to the ICU. He fainted while outside the room. In telling me of Mr. O'Shea's return to the ICU, a nurse-supervisor said it was "a precautionary measure" not because the EKG had indicated he had already suffered heart damage. It seems that one could speculate that Mr. O'Shea's tendency to be active in the ward had been noticed and his return to the ICU was more an attempt to control his behavior than a real concern that his fainting presaged a relapse. One could also speculate that as long as no complications occurred in the patients' recovery as measured by objective medical tests and reports, the staff was not inclined to test how well patients understood instructions or what their attitudes were toward recovery.

In this context, it is not hard to imagine why little, if any, conflict emerged on the ward between patients and staff. The lack of conflict did not reflect a consensus on the best way to achieve the goals of returning the patients to a state of health. Rather, it reflected a lack of mechanisms which could have brought patients and staff members into open awareness of the differences between each others perspectives.[5]

II. The Family's View of Ward Care

In its design, the general medical ward had the potential for greater family access both to patients and to staff than the ICU had. Visiting hours extended from before noon until eight in the evening. Unlike the ICU setting, the ward did not have the same spacial and bureaucratic barriers between staff and visitors; doctors, nurses, patients and visitors all shared the same space. The way the space was arranged, doctors and nurses were visible as they worked in and around the patients' rooms and the nurses' station was not out of bounds to visitors as it had been on the ICU. At any time during the long visiting period, family members could have approached the station and question the nurses directly. Yet, in most instances, this did not happen. Little more family-medical staff interaction took place on the ward than was the case on the ICU. As a consequence, the concerns, doubts and misconceptions about the treatment process which we observed on the ICU continued unabated, and even increased among the family members right up until the time of hospital discharge.

For the families, the ICU had a "halo effect," and like the patients they used what they had seen to be the procedures there to interpret what was now occurring on the ward. Many family members questioned the lack of official sanctions against patient activity, and continued to persuade the patients to remain sedentary. At times they blamed the ward staff for not enforcing a stricter regimen and were critical that the nurses were not around the patient as much as ICU nurses were. Mrs. O'Shea, for example, claimed that the nurses allowed her husband to do things on his own because they were "lazy" and "they take advantage of his good nature." She told me that when she visited, "I was the nurse when I was here." Since she presumed he was out of bed often while she was not present, when she arrived to visit she ordered him into bed. In an attempt to reduce his walking, which he was permitted by staff to do within the room until he was tired, Mrs. O'Shea refused to bring him his pajamas or robe from home. He was left with only the hospital robe which was open in the back and which Mr. O'Shea felt embarrassed to be seen in. When he was sent back to the ICU, his wife told me she was pleased.

It is not difficult to understand why the ICU had such a "halo effect" on the families. The strategy for dealing with the illness on the ICU seemed like "a sure thing." The men had entered the unit under a threat of death and were still alive. People had witnessed that the ICU could efficiently cope with emergencies; in contrast the efficiency and protective ability of the ward was an unknown commodity and from the perspective of many family members it left something to be desired.

In addition to being upset because the ward staff seemed to take a casual, and in the family's view, inappropriate stance toward patient care, wives told me that they were worried that the staff was not placing adequate controls on what patients learned of their conditions. Mrs. Grasso said:

> They speak very frank to them. They come right out and tell them everything. I've been able to get quite a bit of information from Adam. Here is one thing I have to say which left me a little bewildered. One of the doctors, not our family doctor, some doctor had said to him, 'People who have heart attacks would have had them anyway no matter what they did.' And then in the second vein they tell you not to smoke. Not to over-eat, you know, be careful. Now how do they expect a patient who is coming home to start a new life to worry about what they are going to do if they have that in the back of their minds that they're going to get a heart attack anyway?

Mrs. Grasso was troubled that her husband would not tolerate a strict regimen if he did not believe it would bring complete recovery. In effect, she was accusing the medical staff of abandoning its culturally sanctional charge that nurses and doctors are expected to work for full recovery from illness. Coser has commented that "if the hospital is defined as one that 'only' cares for patients who cannot get better, its abandonment of the culturally approved goal of curing the sick has several significant consequences. The scaled-down goal has a direct effect on its members by encouraging either ritualistic or retreatest behavior."[6] Mrs. Grasso, however, did not confront the staff directly with her complaint. Instead she took upon herself the responsibility of convincing her husband that full compliance with a strict interpretation of the medical regimen would lead to complete recovery. This indicates her lack of trust in the staff of the General Medical Ward.

Mrs. Stein also came to doubt the judgement of the staff. She told me that she could "wring the neck of that doctor who told him it was OK to smoke a couple of cigarettes a day." Mrs. Ambrosio was fearful that if the doctor told her husband what he told her, it would cause her husband to lose his will to do everything possible to get well. The doctor told her that her husband would never again be able to do anything as strenuous as changing an automobile tire. When I asked her if she relayed this information to her husband she replied: "If I tell him that in the future you can't do this or that, he will say: 'What the heck, I'd rather not get better.' I'm afraid of that." Her response was similar to Mrs. Grasso's. She emphasized to her husband that full compliance with a strict interpretation of the medical regimen would bring full recovery.

The wives felt that it was important for the patient to believe he would eventually recover fully, even if they themselves believed this to be unrealistic. In this way, they reasoned, the patients would not balk at restrictions on their behavior. Staff members who were "realistic" in discussing the illness and its probable consequences with the patients were considered by the wives to be detrimental.

We can see that the wives questioned the approach to care taken on the ward. They preferred the care on the ICU where patients were allowed no discretion, and where the patients seemed so secure because every action was taken under medical supervision. In effect, when the wives visited they attempted to recreate the atmosphere of the ICU, since they could not count on the ward medical staff to do so. The discrepancy between the wives' definition of the situation and their perception of staff behavior created a barrier to wife-staff communication. The wives felt they had to make up for the failure of the staff to impose strict restraints against patients doing too much.

The ward offered no incentives to give up the first impression. The family members continued to believe that any benefits which might be expected to accrue from activity were small when compared with the potential dangers.

Awareness that it was good for patients to have an active orientation was almost non-existent. They continued the practice begun in the ICU of negotiating with the patients to do less than they wanted to. Patients sometimes resisted their families on this and conflict could develop. One strategy patients had of dealing with members of their families who continually tried to have them remain in bed, or not to talk too much, was to suggest that they visit less. It was common for a patient to urge his spouse to telephone rather than visit every day, or to reduce the actual length of the visits. Sometimes spouses, like Mrs. Stein, did reduce their visiting time because the differences between them and the patients were beginning to cause the expression of hostility.

There was, in general, little interaction between patients and the members of their families about the details of the care or of the kind of adjustments which would have to be made in the lives of the family members after hospitalization. Again the absence of conflict was a sign of failing to discuss different points of view rather than consensus over issues of concern of the parties. Family members continued to be worried about potential harmful effects of open discussion and avoided many topics. Mrs. Grasso, for example, noticed that her husband seemed to be receiving a new intravenous medication. I asked if she inquired of him what it was for. She replied that she "didn't want to press it. I didn't want to speak about it too much." Mrs. Ambrosio deliberately withheld certain kinds of information she learned about the illness for fear it would upset her husband.

Even when important topics concerning aspects of recovery did come up, the conversation was likely to be shifted to more benign areas. This shift was especially likely to occur when the parties to the interaction realized that the issue raised was one on which there were discrepant views. Mr. O'Shea said that there were several times when he and his wife had to "bite their lips" so as not to become angry over something one of them said. When, for example, he spoke of returning to his job his wife would respond that he should not; but when he persisted with this theme she tried to change the subject, rather than argue with him. When she mentioned plans she had at home which he disagreed with (for example, how much money to spend on their daughter's wedding) he kept silent because "I don't want to get into a hassle with her." Normally, he said, he would have vigorously pressed his viewpoint regardless of how angry they both got.

Mr. Grasso was often despondent in the hospital over what his chances were to hold a decent job once his recovery period was over. He was preoccupied with a fear that he would only be able to get a very menial position. I asked his wife if she discussed this problem with him: "Every so often he'll have the paper in front of him and he reads different kinds of want ads....One night he said: 'I'll address envelopes at home.' So you can see he's reading little things like that. And we change the subject, or laugh at him and tell him first one step at a time, first you get well and then take it one step at a time.

Topics having to do with the illness, the recovery process, and future expectations were ones which were avoided by mutual consent. As a result, no exchange of views occurred between patients and families, and areas of disagreement remained dormant in the hospital. Later we will explore how they came to the fore at home, and the problems they caused.

III. Toward Homecoming

Patients concerns and those of the families were for the most part centered in the hospital. Thoughts of home and the problems to be faced after hospital discharge were not at the forefront of awareness. When questions about after hospital care did surface, few people were active in seeking answers from staff. The absence of attention to the post-hospital period cannot be solely attributed to lack of initiative, denial, or short-sightedness on the part of patients and their close kin to matters which would begin to occupy them in an intense way in only a couple of weeks.

Much of what patients and families did or did not do about preparing themselves and their homes for the patients' return home was the result of how they interpreted certain policies and other messages from hospital personnel, and what the ward structure conveyed by implication.

Most of the patients and family members believed that hospital policy was that shortly before the patient was discharged, they would be called to a meeting with several members of the staff - including physicians and dietitians - to be informed about home care. They were, in other words, aware of a certain timetable.[7] Medical care came first. Receiving information about post-hospital roles and responsibilities was placed somewhere toward the end of hospitalization - exactly when no one knew. My questions to Mrs. Grasso on the topic of preparing for home care and her answers are very typical of the other spouses:

E.S.: (Observer) Did the doctors say how long he would be in the hospital?

Mrs. Grasso: They said as long as he keeps progressing, the beginning of next week.

E.S.: Did they say anything yet about what his life style would have to be like?

Mrs. Grasso: No, they said when he's ready to leave they will prepare him for it; the diet, and what to do and not to do.

Near the end of the hospital stay I asked Mrs. Warren: "So at this point you really don't know what his mobility will be?" She replied, "No, I don't, I would like to see one of the doctors, but I'll wait now until he comes home. And then see what he really can do." After a little over a week on the ward, Mr. Ambrosio began to feel concerned about how he would manage at home, especially since he was told he would have to inject himself with insulin every day. When he expressed his concerns, his physician and nurse assured him that all of his questions would be answered some time later. Mr. Ambrosio spoke with me about the schedule for preparing him for post-hospital care:

> I told the head nurse: 'You know its amazing that they have no booklets or literature on the subject. I don't want a medical dissertation on the subject, just plain, simple facts. What am I to do? Why, how and when? It is as simple as that.' She said she would look into it....Then I said (later to a doctor): 'Who gets the follow-up report? After I leave here what am I just number 45559, like a prison number?' He said.... 'Before you leave you will get everything you need. The attending doctor will come in and will give you everything, and instruct you what to do, and what not to do.'

In effect, the medical staff was conveying to patients and family members its particular order of priorities. First, the medical aspect of care are dealt with, and only then are rehabilitation issues addressed. Bloom argues that this two step process of establishing capability before teaching the patient to utilize his capability emerges from a hierarchy of values embedded in modern medical practice: "Especially within the rational, doing, future-oriented cultural frame of reference of Western society, reinforced by the marriage of science to medicine, the technical foundation step toward rehabilitation has been primary." [8]

Patients had few resources with which to press any demands for information they may have had. Not many could take the direct approach of Mr. Stein in dealing with staff. He told me that he had been impatient with his doctor who "kept his motor running" when he looked in on him. Mr. Stein recalled the following incident. One day the doctor asked if he was having any pain. Mr. Stein had pain the night before and wanted to be sure to express it clearly so the doctor would realize it was a different kind of pain than he had been having previously. He paused to construct his answer but the doctor began to step away and Mr. Stein thought he would leave before he could answer. So he lunged at the doctor and held him by the lapels of the jacket. Mr. Stein then said to him if he wanted an answer he would have to wait a moment. Mr. Stein reported that after this incident, his doctor seemed more patient and spent more time with him.

Usually, staff could adroitly use the hospital organizations and their professional duties to parry attempts to elicit information which staff was not prepared to give.[9] Mrs. Ambrosio became so upset at not being able to reach the attending physician - either personally at the hospital, or by phone - that she complained to Group Hospital's Director of Medicine. She was given the explanation that the attending was "very busy." Mr. Ambrosio told me:

> They found out the reason for his rushing. It is not that he couldn't give the time but he has to report at Group Center from one till five, Monday, Wednesday and Friday. Then he has Center office hours from three till seven, two days a week. So he is really on the go from eight in the morning. So he just can't hold my hand.

Using a similar explanation, nurses avoided teaching him how to inject himself with insulin until right before discharge. According to the patient the nurses claimed they were busy that day, or did not come at the prearranged time because there was an emergency on the floor. The patient had other things on his mind besides how to use the needle. He wanted to know for how long he would have to do this, would his wife be able to do it in emergencies - she would have to learn as well, why couldn't he use oral medicine as he had before the diabetes, was it true that after a heart attack blood sugar levels rise temporarily, but fall later, were they sure the insulin injections were really needed. By putting off teaching the patient the mechanics of the procedure, they also avoided having to deal with his questions, and anxieties and arguments against the necessity of a rather distasteful treatment. Also, they avoided having to teach his wife (she never did learn to give the injections). Perhaps they guessed this would be troublesome since the husband did not want his wife involved in this.

Nurses could also claim they lack authority to give out much information. As Mrs. Grasso said: "Nurses tell you only so much, then you have to go to the doctor." As mentioned, the doctors told patients and family members that the time for giving out information was toward the end of the day.

Another factor in why families and patients seemed to ask few questions about the outpatient home care period was that it was widely believed - incorrectly, so as it turned out - that after the patient left the hospital the heart specialists at the hospital would continue to control the care. In other words, it was perceived that there would be no break in the continuity of care. It was believed that while the patient was at home he would be closely monitored and his activities supervised by the same hospital staff of specialists. It was not the opinion of the patients and families that the family doctor would primarily manage the care. If he was to be involved at all, the family doctor was perceived as being a conduit between the patient and the specialist. This made immediate access to information less important since it was believed there would be ample opportunity later to get a thorough understanding of what had happened and its implications for the future lifestyle of the patient.

Most families were pleased that the patient had survived the heart attack and that he was going to be sent home eventually. They saw little reason to complain - even if they felt some amount of doubt and uncertainty about the details of the prognosis and future treatment regimen.

The families, almost all of them, misunderstood the Medical Group system. The family physician, as it turned out, did replace the hospital physicians - who were not all cardiologists anyway, - and if the patient did see a hospital physician again it was only once. This occurred when the family requested a consultation. Then the patient had a chance of being examined by a cardiologist - who might also have duties at Group Hospital.

In a couple of cases the false impression of after hospital treatment was induced by residents who suggested that the hospital attending would follow up.[10] Residents at Group Hospital can be unaware of the special procedures and systems used at Medical Group. They rotate through Group Hospital for three months, as part of their training. Prior to and afterward the residents train at hospitals which utilize a more traditional system where family physicians are involved in the care of their hospitalized patients. Most residents do not wish to practice as members of prepaid group practice like Medical Group, and the orientation they receive at Group Hospital seems inadequate to familiarize them with Group's system.

This can lead to problems. One event which I witnessed stands out from the rest. There was a patient on the ICU who was not given much chance of living if he did not have heart surgery. Yet, in the patient's condition the surgery itself might bring on his death. As the time for a decision drew near, the resident who was involved with the patient said to a group, which included myself, gathered for coffee in the ICU foyer, that he was going to recommend to the family not to have the operation because the chances were too slim and the cost of the operation would be very expensive to the family. At this moment, the head nurse was nearby and interrupted. "There is no cost to the family for the operation," she said, "they have paid a yearly premium for all care." The resident seemed surprised or taken aback that he had forgotten, and declared in that case he would recommend surgery. I heard him later that same day urge the patient - and the wife - to have the operation as the only chance of saving his life.

Another factor leading to the belief that the hospital based specialists would continue the care after hospitalization was the impression created among patients and family members alike that the family doctors were not trained to manage heart disease. There was little confusion, as I had initially expected there would be, over who would provide care for the patient in the hospital. The families seemed to easily accept the idea that specialists based in the hospital were the main providers of care here. They believed that heart attacks required experts specially trained in the care of the heart, and the family physician who gave general care to family members for many "normal" health needs was just not trained to do this. Mrs. Asti's comments on her family doctor are relevant to this point. I asked her what contact she had had with Dr. C., her family physician: "Why would Dr. C. want to see him, he's not a heart specialist. He's a different kind of doctor - he doesn't know about hearts. In fact, he had a heart attack himself once." Some patients like Mr. Warren, were disappointed that the family doctor did not visit them in the hospital because it seemed to indicate a lack of concern. But no one complained that they would get better care by having the family doctor involved. On the contrary, patients and family members alike were agreed that the physician who treated their ills at the Medical Center was "only a general practitioner, and these guys (in the hospital) are specialists" apart from being somewhat annoyed that the family doctor who sent them into the hospital never called or visited - just like patients were annoyed when certain friends or relatives didn't visit - it seemed quite logical that their general practitioners were not involved in the care. This extended to after hospital care.

When the time finally did come for the patient to leave the hospital, the promised discussion with the attending physician proved to be brief, with few concrete questions asked by patient or spouse. It would also prove to be largely inadequate for the needs of patients at home. In at least two cases, there would have been no discussion at all if a spouse had not accidently come upon the physician on the day of discharge. Mrs. Grasso was angry when she told me that only when she met the doctor by chance on the staircase as she was taking her husband out of the hospital did she receive instructions about the diet. The usual procedure was for the physician to give the patient a one day notice of hospital discharge. At that time, he would tell the patient to prepare any questions he might have. In general, the patients had few specific questions and their spouses had less.

The result was that many problems arise in the first few days following hospital discharge which could have been anticipated and perhaps avoided with some prior thought. But the situation minimized the opportunity for the patient and his family to receive information, discuss it and return with questions based on their thinking through the problem.

By the end of hospitalization it was apparent that the views of patients, family members, and medical staff were dissimilar. Trends which began to emerge early in the ICU continued for the duration of the hospital stay. Although during that time, the setting and the care staff changed, the perceptual distance between the parties remained constant. In general, wives were less confident than their husbands that the illness which caused the hospitalization had been arrested, or that the need for hospitalization was over. The evidence indicates that the medical staff was not conscious of the deep apprehension of the family members. At no time did the medical staff address itself to the indications of dissatisfaction and distrust manifested by the family members.

The patients seemed glad to be leaving the hospital, just as they had been relieved to be transferred to the General Medical Ward. However, this in no way indicated that the patients were emotionally prepared for the shift of care to the home, or that they adequately understood what they were to do once they got home. One need only recall the confusion and anxiety which attended the shift of patients from the ICU to the General Medical Ward.

There is no evidence at all that the hospital did not fulfill its responsibility to care for the patients' physical needs. In a space of a few weeks, patients who had arrived there in the most perilous straits were able to return to their families. This fact alone is a testimony to the efficiencey and skill of the medical staff. Yet this improvement in health was accomplished with little participation of the patients themselves, or the members of their families. In effect, the patients were acted upon, and the organized routines of the care setting served to prevent them from interfering with the goals of the institution.

If the illness were of the acute type such an approach might be sufficient. However, the patients did not leave the hospital cured of their medical problem. Hospital discharge merely marked the end of one phase of treatment and the beginning of another. The setting of care and rehabilitation would now be the home where the attitudes and understanding of all the family members would take on a new importance. It is this reality which was not taken into account by the efficient, bureaucratically oriented care system of Group Hospital.

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Chapter 4

Family Structure and the Process of Response to Crisis

Much has been written about the "isolated nuclear family" in modern industrial society. As a sociological concept, the isolation of the nuclear unit indicates that the family has become more specialized than was the case in the past, and that this change is part of a general trend toward differentiation in modern society.[1] As Rodman explains, functions once performed by the kinship system have been assumed by other social institutions: "Not only has economic production been taken over by other organizations than the family.... the schools, the mass media, peer groups, hospitals, voluntary associations, etc., have taken over functions formerly performed by the family."[2]

Parsons and Bales[3] argue that the decrease in quantity of functions must not be taken to mean that the nuclear family has become less important to society. Their point is that society has become more exclusively dependent on the family to perform certain vital tasks, namely, the socialization of children, and the fulfillment of the individual's affective needs. On this latter vital task, Goode explains:

> The modern technological system is psychologically burdensome on the individual because it demands an unremitting discipline. To the extent that evaluation is based on achievement and universalism, the individual gets little emotional security from his work...The conjugal

> family again integrates with such a system by its emphasis on emotionality, especially in the relationship of husband and wife. It has the task of restoring the input-output emtional balance of individualism in such a job structure.[4]

According to this conceptualization of the family's role in our highly differentiated social system, it is clearly indicated that a separation between the family and other social institutions is required because "bureaucratic and external primary groups, unless they are isolated, tend to conflict with each other."[5] Weber's analysis of the restraining influence of the family on industrial bureaucratic development in China may be cited as an example of important conflicting forces in primary group-bureaucracy relations.[6]

Litwak and Meyer have isolated two assumptions which appear to underlie much sociological theory in the area of the family's role in modern society. They write:

> The first assumption is that the primary group and the bureaucratic organization have antithetical mutually destructive atmospheres. Bureaucracies operate on an instrumental basis, stress impersonality... Primary groups operate on a kinship or affective system of evaluation...
>
> The second assumption is that the activities of the primary group are for the most part directly replaceable by those of the bureaucratic organization.... This assumption rests, in turn, on the premise that in a mass society bureaucratic organization is the most efficient way to achieve most social goals. Consequently, if the two types of organization compete, the bureaucracy will tend to supplant the primary group.[7]

This raises important questions for our analysis of family response to the illness crisis, especially after the patient returns from the hospital to complete his recovery at home. If primary groups (here, the family) and bureaucratic organizations (here, a complex medical care system) have "mutually destructive atmospheres," is it possible to expect the family to adequately operationalize the expectations and prescriptions of the medical care system with regard to the patients regimen of care and treatment at home? Would the insights from traditional sociological theory argue against such current medical care innovations as programs which aim to reduce the time patients spend in the hospital and which would place greater emphasis on home-based treatment thereby expanding the role of the family in the treatment process? Can family members be expected to take on functions once exclusively performed in a hospital by professionals? Can a family work with a health care bureaucracy in a systematic, mutually supportive effort to restore a person's health?

As was pointed out in the opening chapter, Parsons and Fox[8] have presented a case in which they argue that the family's social structure does not lend itself to playing an effective medical care role. Moreover, they suggest that for the sake of the patient's return to normal social roles, and the family's own stability, the function of medical care is best carried on outside of the family. Yet, epidemiological data show that because of the chronicity of much illness our population now is afflicted with, many people live for years with the need to control their afflictions with only periodic direct attention by medical professionals. In other words, families *must* be involved with medical institutions in the care process, and the family's role is likely *to increase* in the near future. The men in the present study came home from the hospital *as patients;* hospital discharge signalled a new phase in the management of their heart disease, and one which demanded considerable involvement from others in the family.

It seems plausible to suggest that when a person is recovering from a heart attack at home his family life will be a critical influence on his progress from sick to well, and that without cooperation from those present in the family, health care institutions will be significantly less able to fully achieve the ends to which their efforts are supposed to be directed. A recent statement of the World Health Organization summarizes this position: "Even neurotic individuals can adjust to severe cardiac impairment if they are constantly integrated in a strong supportive, reasonable but not overprotected, healthy family structure, which accepts and understands the illness."[9]

Litman[10] in a case-control study comparing persons who adjusted well to a physical rehabilitation program with those who had a poor response found that those in the former category were likely to live in "highly integrated" families. In contrast, the others were more likely to be members of "poorly integrated" families. Several studies of reinstitutionalization for mental disturbance have also documented the role of family factors to the achievement of therapeutic goals.[11, 12]

Given the reality that thousands of individuals receive home based care, theoretical interest in the coordination of activities of primary groups and bureaucratic organizations in the shared task of caring for illness converges remarkably with the practical need for information along these lines. Not only is this so because the medical care system has been shown to require cooperative involvement of the family, but also because coping with illness can become an intolerable burden which can threaten the well-being of the family unit itself. Croog, Levine and Lurie raise several relevant issues for research; for example:

> The effects of illness on family integration, family consensus, parent-child relations, decision-making patterns, and family authority structure.... What is the pattern of change in each of the areas mentioned when control variables designating different types of families are used in analysis?.... What is needed here is comparison of patients with differing outcomes of illness or differing levels of adjustment in regard to such variables as levels of (family) cohesion, integration of types of decision-making patterns.[13]

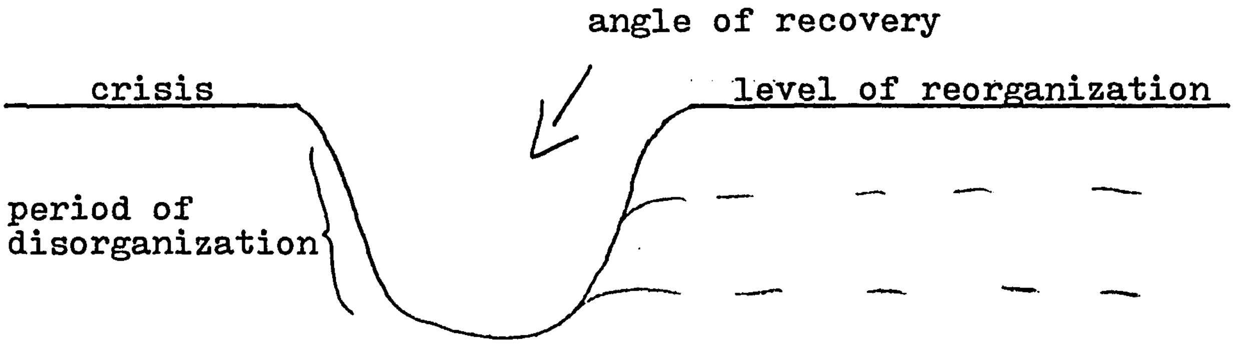
In order to address issues raised by these theoretical and empirical observations, I have analyzed the response of eight families to the crisis engendered by heart attack from the standpoint of the <u>process by which problems are coped with</u>, <u>and the variations in the adjustment process which are related</u>

to particular types of family structure. I have focused on such questions as: Are there certain types of families which because of their structure or value climate are enabled to make the adjustments required by the medical regimen without experiencing significant losses in interpersonal harmony or group stability? Are there points in the aftermath of the illness onset which pose especially onerous burdens on a family with a particular social organization? Are medical care systems better able to integrate their activities with one type of family than with another? An additional question centers on the health care system itself: Do the unique organizational features of a prepaid group medical practice facilitate the integration of the family's role with the therapeutic process?

I. Conceptualization of Family Response to Crisis

Much sociological inquiry into the impact of crisis on family organization has taken as a point of departure the framework of Reuben Hill.[14] His now familiar ABCX formula postulates that A (the stressful event) → interacting with B (the family's crisis meeting resources) → interacting with C (the definition the family makes of the event) → produces X (the crisis). This process can be further illustrated by Hill's schematic profile of the adjustment process which depicts the order of events following a crisis: crisis → disorganization → recovery → reorganization.

This is represented by the following diagram.[15]



It is postulated under this formulation that the same factors which are instrumental in producing the crisis (the nature of the event, the family's resources, the definition of the situation), should affect the process of adjustment to crisis. That is, the length of time it takes to reorganize and the level of reorganization finally attained can be expected to reflect factors in family life which are associated with crisis-proneness or crisis resistance. Drawing on the work of Cavan[16] and Angell[17], Hill argues that favorable adjustment to crisis occurs within families whose pre-crisis stability was high to begin with. The factors he suggests to be conducive of good adjustment include: family adaptability, family integration, affectional relations among family members, good marital adjustment of husband and wife, companionable parent-child relationships, social participation of wife, and previous successful experience with crisis.[18]

There are reasons for questioning the sufficiency of the idea that the "well-adjusted" family has the means to cope successfully with crisis. On methodological grounds, "welladjustedness" is a difficult concept to operationalize. Often it is more reflective of value bias on the part of the researcher than a condition of positive, fulfilling, stable family relationships. Moreover, in many studies the subjects define the term themselves, thus making comparisons between studies difficult. Lively asserts that "the continued use of 'marital happiness','marital success', and 'marital adjustment' is detrimental to the development of precise analysis and theoretical formulations of marriage as interactional behavior. These and similar evaluative terms involve assumption of knowledge about the consequences of marital interaction without establishing the dimensions of the interactional process."[19]

Moreover, even if one assumes that the well-adjusted family can be identified, research has shown that the grounds for family stability, adjustment, and satisfaction can vary from one unit to the next. The work of Hawkins[20] has shown, for example, that stability can be high in families where affectional relations are not high. In a review on the relationship between family structure and happiness and stability in marriage, Hicks and Platt assert that:

> Family sociologists have postulated for many years that at least two basic marital types co-exist in the United States: the institutional and the companionship...In the institutional marriage adherence to traditional role specifications, custom and mores would be factors which would be most significant to the success or happiness of the marriage... The companionship marriage places greater emphasis on the affective aspects of the relationship.[21]

The review goes on to isolate the most important variables in the institutional family. Included are: congruence in role perceptions, and compatibility between role expectations and actual performance. As far as the companionship style of marriage is concerned, the most important factors involved in stability and happiness include: feelings of affection, sexual enjoyment, and companionship. It is not suggested that if one aspect is present, the other is absent; only that for many families either companionship or instrumental factors receive greater emphasis.

There are other styles of family living arrangements which research has identified. For example, companionship and role compatibility may both be valued very high. Hansen and Hill[22] have suggested that a family of this type would be particularly resistent to disorganization following the onset of a crisis. The stage of the family lifecycle is also important in assessing the requirements for family adjustment. Pineo[23] reports that in the later years of marriage couples experience a loss of intimacy and reduction in shared activities. While this "disenchantment" can result in serious marital instability, for many couples a new integration is worked out. Happiness might not be as high as it once was, but the marital bond remains intact. Ballweg[24] has shown that the division of labor in the home undergoes a change after the husband's retirement. With more leisure time, the man assumes some of the household chores formerly assigned solely to the wife. Even prior to the retirement phase, the wife's lifestyle can undergo important alterations. Once the children have grown, she may find less to do at home and begin to form attachments to social groups and interests outside the home. While in the early married years the family may have had a highly differentiated, role segregated social structure with much emphasis on affection and companionship, the later years may see a change to a role exchange, low companionship family style. If families can show marked differences in organization, and, in turn, what they require to maintain their cohesion, can they be expected to be equally equipped to handle periods of crisis? Furthermore, is it not plausible to expect families which differ on important structural and attitudinal dimensions to develop different strategies for coping with crisis and therefore show contrasting patterns of adjustment?

Farber[25] suggests that a productive way of advancing knowledge about family crisis interaction and organization would entail identifying and analyzing the new family processes following the advent of a crisis. He argues that:

> If the crisis stimulus merely produces disorganization then there is little that can be done to predict the nature of the patterns of family reorganization. However, if the crisis is regarded as inducing a certain type of distorting process to the initial organization then this new process can eventually be identified. With this identification of the distorting process, the researcher can predict types of strategies developed by familes to handle this new process.[26]

Farber's approach to crisis adjustment as a process contrasts in its emphasis with Hill's formulation which is more like a stimulus-response approach. It is compatible with that taken in the current study; that the adjustment processes developed by families after the onset of the illness crisis can be related to the structure and culture of the nuclear unit. This has been supported by the writing of Parad and Caplan[27] and Meyerowitz and Kaplan.[28]

From my contacts with families following the hospitalization of the husband-father for heart attack, I was struck by the differences in the way the groups responded. They differentially employed, what Parad and Caplan[29] have labeled, "intermediary problem solving mechanisms" to cope with the unexpected event. As I got to know the families better, I began to see that these patterns of behavior were expressions of the family's social structure and value orientation. Further, by comparing and contrasting coping behavior as the crisis unfolded, especially after the hospitalization period, I became able to identify three major streams of response, representing distinct approaches to solving the problems which confronted the families. It was not so much the nature of the problems that was different, as it was how these problems were perceived, and the solutions which were proposed for them. It is of considerable interest that there was a correspondence between how problems were defined and coped with, and the structure and culture of the families. Each distinct response pattern was associated with a particular family type.

Florence Kluckhohn[30] has noted that family value orientations are deeply rooted and so pervasive they markedly affect the patterns of behavior and thought in all areas of activity. Important values and beliefs are, in turn, expressed in the way that family roles and interpersonal relationships are structured. It is not surprising, therefore, that illness response is related to a family's committment to a particular set of values and corresponding behavior patterns.

II. Family Types

In the present study, the two parameters of family life that appeared to influence most patterns of coping were <u>role structure and companionship</u>. Three types of families were identified, and analyzed in terms of the patterns of coping with illness.

A. Role Differentiated Families

> These were families in which particular members were identified with, and responsible for specific tasks. Smooth family functioning depended on compliance with this arrangement.

B. Role Exchange Familes

> These were families in which tasks were commonly performed according to personal preferences of the members rather than a strict assignment of particular persons to specific tasks. Smooth family functioning depended on the ability of the group to accomplish its task without inhibiting freedom of choice of its members.

C. Role Dissensus Families

> These were families in which there was considerable disagreement between spouses over whether role differentiation or role exchange should prevail.

There were two families which were primarily role differentiated: the Grasso's and the Goldberg's. Four were primarily role exchange: The Asti's, Polski's, Warren's, and Stein's. Two were divided on preference for role arrangements: the Ambrosio's and the O'Sheas.

There was a connection between role structure and companionship. In the role differentiated families, intrafamilial companionship was highly valued both in terms of interaction within the home, and in joint participation with the outside world. In the role exchange families, intrafamilial companionship was not highly valued, either in terms of interaction within the family or with the outside world. In these families, members participated separately with kin and social networks. In the role dissensus families, the member who preferred role differentiation also valued high intrafamilial companionship; while the member who preferred role exchange valued separateness both within the home and in dealing with kin and social networks. An illustration of how the groups differed in companionship can be given in the area of recreational activities. In role differentiated families, spouses usually recreated as a unit - they socialized together with a common friendship network. In role exchange families, on the other hand, separate socializing was more common - each spouse had a separate friendship network in which he/she expressed individual interests.

In the literature on family relations opinion is divided on the relationship between division of labor and companionship. One view, represented by the work of Bott[31] and, more recently, Pratt[32] is that companionship is fostered by a sharing of tasks. Bott reported that the role sharing families she studied were characterized by..."their high standards of conjugal compatability, their stress on shared interests, on joint organization."[33] She goes on to state that in these families sexual differences were minimized. Westly and Epstein, taking a different view, have observed of families that share roles: ..."the members of such families face serious problems in maintaining their relationships and communicating respect and affection for each other....they must seek (it) elsewhere.[34] Kephart[35] would agree that role sharing families do not foster a "we feeling" among members.

In our families, exchanging tasks did not result in members sharing common experiences. Freedom from rigid role responsibilities allowed role exchange family members freedom for maximum participation in their own separate interests and social groups, a kind of activity which was highly valued in these families. The norms allowed individual interests to take precedence over those of the family, in most cases. In contrast, the highly differentiated families, where role segregation prevailed, seemed able to foster sharing of common experiences while preserving distinctions based on sex and generation. Roles, while distinct with regard to who played them, were interconnected and this encouraged communication and a high degree of awareness of each other.

These distinctions are relevant for assessing the meaning the family has for its individual members. In the role differentiated-high companionship families, members were dependent upon others in the family to provide a range of day-to-day services. Since roles were not normally interchangeable, failure of one person to fulfill his obligations deprived the others of services they had come to expect. In addition, role differentiated members depended on one another for regular affective support. Spouses especially had few resources outside the family to which they could go to fulfill affective needs. In a very real sense, their chances for self actualization were located within the bounderies of the nuclear family.

This was not the case for members of role exchange families who expected flexibility in family life with regard to when and by whom tasks were accomplished. These persons were generalists in that they had experience in performing a range of family tasks and did not have to depend on the regular role performance of others - at least not to the same degree exhibited in role differentiated families. Nor were these members without outside sources of significant emotional support. <u>Chances for self actualization were not so highly dependent on their life inside the family</u>.

Conflict resolution differed in the two family types and reflected the committment of the members to a group or an individual orientation. In the role differentiated families, conflicts tended to be resolved through a mutual exchange of opinion leading to a joint solution. Members were expected to arrive at solutions which resolved the differences between them. The problem was not solved if the outcome led to a decrease in intrafamily interaction and an increase in hostility. In role exchange families, differences among members were allowed to coexist. The solution to problems often was to increase the social distance between people thereby decreasing interaction. In the former case, hostilities were likely to result in face-to-face arguing, and in the later case in members not talking to one another.

In the Polski family, a role exchange-low companionship type, the spouses disagreed over where to spend their time. He had a strong preference for living mostly in their country home, while she wanted to spend a lot of time in their city home. This difference was handled by periodic living apart. Mrs. Polski would return to the city alone and spend several days there going to meetings in her church and visiting close friends whom she had known since her girlhood. A contrasting mode of problem solving took place in the Grasso family - a role differentiated group - where one spouse would not go alone to a social function if the other could not, or did not want to attend. A recent issue on which the family members were divided concerned the purchase of a business. Mr. Grasso wanted to use a significant portion of the family savings for this purpose. Mrs. Grasso wanted him to remain at a salaried occupation. The disagreement lasted a long time until Mrs. Grasso felt they had to find a way to agree since "he had his heart set on it." The couple worked out a compromise (Anthony, their son, supported his father). The husband agreed to a smaller store, requiring relatively small financial investment, and one which would be close to home so they could still participate together in the extensive social life they had. To secure his wife's support, Mr. Grasso also agreed that the business would not be "one of those junky discount places," and opened a small gift and greeting card shop. In addition, he agreed with his wife's wishes that she have input into the quality and kind of items the shop carried.

This family decision making process suggests that in this role differentiated family neither spouse was able to act without obtaining the cooperation of the other. In the end, each got less than he or she originally hoped for. Mr. Grasso settled for a smaller store, one which did not fully measure up to his original plans. He was responsive to his wife's point of view. Mrs. Grasso, while her preference was for no store at all, felt she could not persist in her opposition to the store in the face of her husband's strong desire, and his role as economic leader of the family. Rather than challenge this role and his identity by thwarting his plans completely, she gave a conditional approval.

The above incidents point up the different requirements for meeting personal goals in these two types of families. In role exchange families, members did not need to participate with each other to fulfill their aspirations; in role differentiated families working with others in the group was a necessity. It follows that there would be a higher tendency in the role differentiated families for interaction to be characterized by negotiations as members seek to control or influence the behavior of others in the performance of role activities. Since the direction the role differentiated-high companionship family took depended on highly coordinated joint activity, members had a stake in monitoring what others did and an interest in seeing to it that it met their expectations. As Kluckhohn[36] points out, within role prescriptions there is enough flexibility and ambiguity for the role player to exercise individual judgement - which might, and probably often does - clash with another's expectations. For these reasons, one would anticipate that the issue of power and control would be highly important and surface often in role differentiated families of the type I have described.

II. 1. Role Dissensus in Family Life

The relationship between family organization and individual need - gratification comes into sharp focus when examining daily life in the two role dissensus families. (The Ambrosio's and the O'Shea's). Both wives were very often unsuccessful at having their husbands adhere to a segregated system of task responsibilities, which would have brought husband and wife together on a more regular basis.

The Ambrosio's are a retired couple with two married children. In telling me of their childrearing days, Mrs. Ambrosio spoke of the pleasure she took from her homemaking role. She recalled:

> I have friends when their husbands are coming in the door from work they don't know what they are going to make. I think a table should be set when a man comes home from work. That is part of a home. When I observe that I say I'm never going to complain. That is a joy, to have the food ready. They say, 'What am I going to take from the freezer?' I always plan the day before; and then look forward to making it. When the kids would come home from school, they would say, 'What have you got?' They would take the cover off, open the oven. We used to do that at home."

Before her husband retired, she was "in control of" housekeeping chores like shopping and preparing food, housecleaning and bill paying. She claimed she enjoyed being responsible for and carrying out this function. Mrs. Ambrosio reported that Mr. Ambrosio also enjoyed domestic chores, but that his occupational role precluded his usurpation of Mrs. Ambrosio's realm of activities.

Studies show that after retirement, it is not unusual for a man to participate in some aspects of tasks formerly done exclusively by the wife. But as Ballweg[37] points out, the assumption by the husband of additional household duties need not constitute a disturbing force in the relationship. In the Ambrosio family, however, it did. Since his retirement, Mr. Ambrosio has attempted to assume the major functionary role in the home. By his remarkable energy - he said he has slept no more than four hours a night all of his adult life - he has been able to initiate chores before his wife has a chance to do them. The following is part of his description of a typical day at home prior to his heart attack:

> My normal procedure it to get up early, make the coffee, have a cup, get the newspapers, pick up the milk from my friend who has a fruit stand, be back by 7-7:30, have another cup of coffee, read the paper and by 8:00 I am in the supermarket. (Observer E.S. - When is your wife up?) I told her to sleep. She sleeps. When I get up she says, 'Where are you going?' I say, 'Go back to bed. I'm going to get up. What can you do, it is still dark.' By nine I have avoided the rush at the supermarket, got all the goodies done.

Having these household duties taken from her has had a profound effect on Mrs. Ambrosio. In commenting on her feelings about this she revealed a negative self-image as a result of having a minimal family role: "I feel so stupid in so many things. For instance like the light doesn't go on. He always does it, does everything....and I don't know how. I feel like now he should let me."

During the interviews she spoke of her husband's failure to acknowledge her ability to accomplish meaningful tasks around the house, thereby making her feel like a child. What she would like is to be identified with a wider range of activities similar to those she had prior to her husband's retirement and have her husband respect her hegemony over these areas of their joint life. He then would be her role partner. She would like her husband to remain responsible for "the masculine chores," painting, repairing, taking out the garbage, etc., but not chores in her "domain": preparing meals, shopping for food, cleaning, etc.

In the retirement phase, Mrs. Ambrosio often has tried to recapture some of the prized household activities for herself. Over her husband's objections she would meet him at the train station with the car in inclement weather, buy him clothes, and generally try to establish some control of family functions. She has regularly attempted to influence what is purchased at the supermarket. Sometimes this contest results in task duplication. For example, after Mr. Ambrosio has cleaned the kitchen his wife will repeat this chore when he has finished. She has often insisted that it is her job to do this.

Mrs. Ambrosio now belongs to a number of community organizations. In most she has risen to a position of leadership. She told me that she joined them because she had nothing to do at home and would gladly end her participation if the pattern were altered.

In spite of her extensive out-of-the-home role, her most significant point of reference is her husband and her family, and her vision of an ideal family situation includes husband and wife linked through the coordination of separate activities, dependent upon each other, respectful of each other's domain, sharing some activities including decision making, and being regular companions to each other. Without his cooperation, she cannot actualize her life goals.

There is a similar issue active in the O'Shea family. Mrs. O'Shea, like Mrs. Ambrosio, values high role differentiation and what this implies for reciprocal, coordinated behavior.

Mrs. O'Shea perceives the marital relationship as comprising an array of reciprocal role relationships bearing on various aspects of marriage and family life. Mrs. O'Shea's conception is more narrowly drawn. An example of their general contention is over housekeeping roles. Mr. O'Shea would like dinner, for example, to be an activity which members participate in according to their outside priorities. If he is late from work, or has a community meeting to attend he prefers to make his own dinner when it is convenient for him. But in his wife's view, preparing dinner is an activity covered by her role as wife and his absence deprives the role of meaning. Outside activities should not interfere. It is a meaningful part of her role if he reciprocates the activity and partakes of the meal at the time it is prepared. She perceives her various housekeeping roles as containing privileges as well as obligations including the right to organize the participation of others. She wants to mark clearly the distinctions in the family over tasks and stresses the needed complementary of their roles. Some specific areas of contention in the family are: transportation, she wants to shop but wants him to drive her; housecleaning, she wants to define which chores will regularly be performed by what person.

An important issue for Mrs. O'Shea is companionship. Because of his extensive community involvement, Mr. O'Shea is out of the house most evenings. His wife is home alone. She argues that as her husband he is obliged to give her companionship. He argues that she should not rely only on him but find substitute companions. This extends to their socializing with others. She claims he leaves her to "table hop" at parties, and she must find alternate partners to dance and talk with. She has friends with whom she can recreate and she does. But her notion is that her status as wife is limited by his unwillingness to coordinate his behavior with hers.

Both wives in the role dissensus category are selective in their preferred view of how family relationships should be ordered. There are some family activities Mrs. O'Shea definitely does not want her husband to be involved with.

Her selection is along traditional male-female lines. She does not want him to do laundry, or cook or take an active role in decorating the house. She questions the maculinity of men who do these activities. Mrs. Ambrosio wants to take over from her husband primarily those roles which traditionally are ascribed to women: shopping and preparing food, house cleaning, etc. She wants him to be active in the masculine roles, and she says she admires his manliness and likes being supported by him.

II. 2. Role Exchange Families

In each of the four families whose division of labor was of the role exchange type, it was obvious that the family members spent a considerable amount of time apart, engaged in individual activities. There was little attempt to find mutual interests, or to build group activities into family life. Recent articles which have attempted to identify factors associated with marital cohesiveness and dissolution have reported that participating separately in external networks can weaken the marital bond. Scanzoni writes:

> Consensus over goals and means comes chiefly through voluntary mutual participation in external networks and interests. To the extent that the couple is mutually integrated into these external networks it will share common values and norms, hence resolve conflict by means of other than dissolution, and thus remain organized.[38]

These role exchange-low companionship families did not appear in danger of breaking up in spite of their considerable lack of a spirit of togetherness. Levinger[39] has suggested that the attractiveness of outside groups and interests is only one in a complex of factors affecting marital stability. Another is the extent to which there are restraints against leaving the group. Three of the four role exchange groups in this study were practicing Roman Catholics, a religion which prohibits divorce on moral grounds. But external restraint against marital breakup was not keeping unhappy couples together. There were no signs that these families were especially conflict ridden, or that the couples would have liked to separate. What seems to be the case is that the attractiveness of the family for the members inhered in allowing them maximum freedom for participating in outside interests. Role exchange family members were committed to the family even though strongly attached to external networks and interests. While members were separate, they were not isolated from one another. They did contribute to the family be being concerned for each other's welfare and in performing household tasks. But in keeping with family expectations they placed a high priority on outside activities and did not hold themselves to - or expect others to conform with - a rigid system of role activities.

A similar pattern of family living has been reported by the Rapaports in the "dual career" families they studied.[40] The participation of the spouses in occupational careers they enjoyed did not lend itself to a role differentiated division of labor in the home. Rather, a role exchange prevailed. In one case analysis, they described a typical dual-career family pattern:

> In the Bensons' activities within the family, flexibility has been a keynote, The emphasis is placed on different activities as demands change.... There is a lack of emphasis on 'servicing' one another but rather an emphasis on individuals looking after themselves....Daily routine food shopping is done either by Mr. or Mrs. Benson depending on whoever is going out at the time... Mrs. Benson usually makes supper but Mr. Benson may do so and the children are good at helping.[41]

It is evident that for some families flexibility in household tasks assignment is essential to successful functioning of the members in their external worlds. It is hard to imagine their family bonds being strengthened by role differentiation. The evidence from the Rapaport study suggests that durable, and satisfying family relationships can coexist with a high degree of separate external participation and a role exchange division of labor.

In one of the role exchange couples in this study, the Steins, both spouses were employed full time in jobs they enjoy. She worked days, he worked nights. They did not actually interact face-to-face except on weekends. By the time Mr. Stein came home, his wife had already gone to sleep. Neither person thought this arrangement posed difficulties to their relationship. On the contrary, they both claimed that it was the reason they get along so well. Both said that seeing each other only on weekends "there is no time for fighting." They described the little time they spent together as warm and congenial and indicated that it is sufficient for their needs.

Both enjoy their work and their privacy. Mrs. Stein interacted with people all day as a customer representative. At night she wanted to be alone - often, she said, she disconnected the phone. She enjoyed sewing and watching television. Companionship was what she did not want in her spare time during the week. She did not enjoy cooking and she prepared simple meals for herself. Later in the evening, Mr. Stein either warmed up what his wife had left him in the pots, or he prepared something new for himself.

Mr. Stein reported he had no difficulty spending his free time during the week alone. He had several interests which his wife did not share although they affected her. One was playing the stock market. He used a percentage of the family income to make investments and did a large amount of research. It was like a hobby. He rarely told his wife the results; she told me she did not care to know. She said as long as losses did not threaten their present life style she did not care what happened to the rest of the money.

On weekends, the couple caught up on accumulated chores. Their approach to this was casual since neither enjoyed doing house cleaning, gardening, repairing or planning and shopping for meals, and other similar activities. There was some pattern to their activities in the home. Mrs. Stein more often cleans the home, and Mr. Stein usually expected to keep the garden neat and take care of large home repairs. But even here there was overlap because each tended to minimize the amount of time spent in these activities. Mrs. Stein, for example, saw to the gardening if she felt it had gotten to the point of being a noticeable eyesore in the neighborhood. Her husband straightened up the house when it became too sloppy for his taste. Neither expressed criticism of the other for this to me. In addition to doing most of his own cooking, Mr. Stein also helped his wife plan for the shopping by specifying what foods he would like purchased for one week. She usually purchased the food. As far as serving meals, this chore was shared. They ate their meals on weekends while watching television, and depending on who was more involved in the program, or who was more tired, one or the other served the meal.

The Asti's are a family with two children (19 and 20 years of age) living at home. The wife did not work. Yet a similar pattern of role exchange and separateness prevailed. Both spouses took pride in the appearance of the home and worked hard at keeping it attractive and in good repair. Mr. Asti actually enjoyed household chores more than his wife did. In fact she was planning to return to full time work. Mr. Asti was content to spend his spare time doing chores around the house. However, he insisted that he choose when and what to do. When I asked him for examples of occasions of conflict with his wife he identified times when she has tried to tell him what chores to do when he had other plans. When I asked what qualities he most admired in his wife he responded: "Like me, she never calls a tradesman to do repairs but does them herself." She had her own toolbox and made household repairs. It was Mr. Asti's habit to do major repairs around the house, and to service the family cars. However, he was not pleased with this arrangement, and had been trying to involve his wife and daughter more in these activities. He wanted them to know how to make minor repairs on the car, and to keep them serviced. His claim was that since they drive this is useful information, and being dependent on him limited their own ability to be self-reliant, a quality he admires in people. He has suggested they become involved but has not insisted.

The family commitment to individual choice comes through in examining occasions when a family member wanted help with some activity, and in the relationship between parents and children. Occasions arose when Mr. Asti would ask one of the children for help on a chore. Often they complied. But it was understood that their own priorities came first, and there seemed to be no insistence that a child help at home when he or she had something else planned. No pressure or threat of punishment accompanied a refusal of one member of the family to help another. Another limitation in intrafamily helping behavior involved the preference of members to structure their activities according to their ideosyncratic preferences. They chose to do things in their own time and in their own way. I was told by the parents that they are hesitant to seek the assistance of their children partly because they may have to wait for the children to become free to help. Parents had definite ideas about how they wanted chores done and preferred doing them themselves thus guaranteeing a certain level of task-performance. Mr. Asti said: "John has a tendency to forget - like taking out the garbage. That's why I try to do a lot of things myself." Notice that there is no attempt to insist that John conform to his father's expectations.

Starting when the children were in their early teens, they were given a great deal of personal choice in their behavior. Now, for the most part, their parents considered them adults. Both parents expressed to me areas where they would have liked the children to behave differently - around the house and in their career pursuits. Yet, the parents, for the most part, did not attempt to impose their own views onto their children. One exception to this rule was Mrs. Asti's concern that her daughter Rose stayed out late in the evenings. When Mrs. Asti tried to involve her husband in this dispute, he criticized his wife for interfering with Rose. Mr. Asti himself was very disappointed with what he perceived as lack of initiative on the part of his son, John, in finding a secure job. Yet he claimed he did not attempt to encourage him anymore because "he's a man now." He was concerned about his son and wished he would succeed but did not actively interfere. While Rose was in control over her own behavior at home, her parents gave her an allowance since she was in college and had no income of her own. It follows the role exchange model that each parent gave her a separate allowance. Neither knew what the other gave.

The children were not in the habit of informing their parents when they went out, or when they would come home. There was no constraint on them to take meals at home. If someone missed a meal he or she cooked separately. Mrs. Asti would leave the food on the stove for anyone to reheat. Although Mrs. Asti regularly cooked dinner, she exerted no control over the behavior of others around meals. Her role as family cook was not one which called forth a reciprocal response from others, and stands as an example of the general lack of interdependence of members in the household.

The spouses pursued independent recreational actitities. Mrs. Asti had her own set of friends who she saw weekday afternoons and weekend evenings. There was some joint recreating - both spouses like to go to the racetrack - but each enjoyed leisure activities the other did not. The result was that each found companions with whom these interests could be expressed. A favorite pastime of Mr. Asti was reading which he did a lot on the weekend evenings at home. Mrs. Asti liked playing cards, and going to a friend's home for games was a regular activity for her on weekend evenings.

I asked the members to describe the way conflicts were most often resolved in the home. Mrs. Asti said: "We try to ignore one another." Rose said that when one of her parents is in a "nasty mood" she spends more time away from home until the atmosphere has changed.

One of the characteristics of all the role exchange families is the willingness of the members to accept flexibility in family activities. Convenience, personal choice, the demands of time were the major organizing factors in the homes. The Warrens are a retired couple who have no children. They both worked most of their married life and throughout it have done most chores according to who had the available time. This has continued to the present. There were some weeks when Mr. Warren did the shopping since he was the only driver and was able to get to the market more conveniently. However, he did not always do it. Sometimes his wife wanted to walk to the shopping district and took along her shopping cart. She seemed to do the cooking for the couple, but it was evident as I spoke with the couple that Mr. Warren contributed to the planning of meals, and was knowledgeable about food preparation. When they both worked he would begin preparations for dinner if he arrived home earlier than his wife.

The pace of life for the Warrns' was slow. He spent a good deal of his days and evenings watching television. She said she "usually just mopes around", doing crossword puzzles, sewing, sitting in the garden. They both indicated a good deal of boredom and apathy toward their everyday lives. Doing household chores may have provided occasional relief from the boredom. Mr. Warren sometimes took the laundry to be done; or, if he did not feel like it his wife took care of it. Except for one day a week when Mr. Warren drove a cab and his wife did "heavy cleaning" the content of the day's activities depended on personal considerations rather than any organized plan.

Even though the couple was in close proximity for a good part of most days, Mr. Warren reported that he usually had little idea of what his wife was doing. Except for visiting relatives and attending church social functions together, the couple found few activities which they enjoyed together. Mr. Warren's major daily opportunity for social intercourse occurred at the end of the day when he sat in front of his home and greeted his neighbors as they came home from work. Both spouses attested to the fact that they talked little to each other during the day. This seemed to be part of their general apathy rather than to any overt hostility between them.

II. 3. Families in Which Both Spouses Value and Practice Role Differentiation and Companionship

In the Grasso and Goldberg families, the practice of having family tasks allocated along traditional lines of sex and generation was valued by all the members. In both families, the wives were responsible for traditional female tasks of shopping for, preparing food, all regular house cleaning, mending and laundering clothing, decorating the home, etc. The husbands had some housekeeping chores - cleaning walls, moving furniture, making structural repairs, caring for the family car, other male oriented tasks including their role as economic provider.

Mrs. Grasso worked four days a week. She began when her children were in their teens. She and her husband reported that it was agreed beforehand that she would continue to do all the household chores, and would leave her job if it interfered with the smooth functioning of the household.

On any given evening during the week the observer in the home might witness Mrs. Grasso doing the following chores until after 11 P.M.: cooking, dishes, laundry or ironing, light housekeeping, preparing her clothing and person for the next day's work. During this time her husband and son might be watching TV. There was no expectation that either should assist her in these chores although they often kept her company by talking with her when she worked. After dinner Mr. Grasso recorded the day's receipts from the family business. He put stock for the next day into his car - it was stored in the basement - and then was free to do his own household chores, or watch TV, read and do whatever he pleased. The family's friends followed the same pattern, I was told. On the other hand, Mrs. Grasso had no hand in the operation of the family business, which was her husband's responsibility.

Yet the role differentiated style of living brought the couples together on a regular basis. For example, the activity of food buying, preparation and serving was the sole responsibility of the wives in the Grasso and Goldberg families. But transportation was the husbands' task. Both sets of spouses went to the market together, but the husbands' had little or no input into what was purchased. (Mr. Grasso did say: "I pick out some junk food".) Mealtimes in the role differentiated families were joint activities. Members were expected to eat together. If someone wanted to be absent he was required to notify the woman in advance. Since she had the responsibility of preparing meals, the wife expected others to respond by being present. She had control over these aspects of the family's activities.

Parent-child relationships in the Grasso family provides a sharp contrast with those described above in the Asti family. Anthony, twenty-two years old, was formerly married and has a child, and at the time of his father's heart attack was manager of a fast food franchise. Yet in the home, both he and his parents emphasized that he was still a child and subject to parental restrictions. For example, if he was not going to be home by a certain time in the evening, he was required to call his parents and let them know when to expect him. His father was very explicit in telling me that Anthony had to be careful how he spoke to his parents and not act toward them "like friends on the street."

Mr. and Mrs. Grasso felt that they still had an obligation to guide and counsel their son. Mrs. Grasso was disappointed that Anthony left college for his present position and had been making an extensive effort to persuade him to return. In the home there was regular sharing of interests. Father and son watched and discussed sports, and they attended sporting events together. At the dinner table, politics and religion were discussed with father and son usually disagreeing with Mrs. Grasso. Anthony expressed considerable satisfaction over activities which he and his parents engaged in together. A recent event was singled out in one of our conversations. He said he urged his parents to watch the film "Godspell" on television. At first they were skeptical about a non-traditional treatment of a religious subject. But they watched it and enjoyed it. Anthony reported that he was delighted with their response. He felt he had contributed to an enjoyable family experience.

Life did not always run smoothly in the Grasso home, and at times conflict developed. The most frequent source of interpersonal disharmony occurred as a result of Mr. Grasso not coming home in time for the couple to meet their friends, or visit relatives. Operating the family business often entailed long hours for Mr. Grasso. His wife claimed that this deprived her of participation in activities she enjoyed. She would not go alone to social functions. Since they have owned the store they have not been able to go on weekend trips, which was something they did regularly while Mr. Grasso had a salaried position with a large firm. Prior to the heart attack, the store was a recurrent point of disagreement. Mr. Grasso conceded that his wife had a right to expect his companionship and expressed sympathy for the deprivation she felt. However, he claimed that the business was just beginning to show profits and he did not want to see his efforts to build the business go for naught. He argued that he needed the business to insure his role as family breadwinner. Five years ago he suffered his first heart attack and believed that this prevented him from getting a job suited to his interests and talents. Owning and operating the store was consistent with the image of masculinity he desired to have and project. He told me he would deeply regret having to depend on his wife's income. He seemed to feel caught between his need to insure a positive self-image based on his occupational role and economic leadership in the family, and his felt obligations to his wife.

III. Role Reorganization During Home Care

It is repeatedly pointed out in the literature that a major problem families face once a member is stricken with serious illness is the area of role adjustment.[42] In some families, this is a technical problem. The services performed by the ill person cannot be adequately taken over by another and the members experience need deprivation.[43] For problems such as financial loss, need for help with chores, transportation, and so on, important assistance can come from outside the home, from friends and relatives.[44] However, sudden, drastic change in the capacity of persons to behave according to former value expectations and priorities can be a problem of a more significant order, less easily dealt with. For some individuals, the loss of function does violence to their concept of self and to the image held of them by significant others.

In view of the magnitude of the alteration in behavior resultant from heart attack, the extended period of convalescence, the uncertainty about how complete will be recovery, it is not hard to understand how disparities among role concepts and self concepts can arise during the home care period. A situation can easily be conceived of in which consensus over role expectations begins to break down. Discrepencies may arise among the family members over such matters as what are realistic family goals given the new situation; what should each member expect of the other in terms of role performance, to what extent should individuals be expected to alter their personal lifestyles, in and out of the home. Familiar and valued patterns of behavior which prevailed for the members in the home may have to be reexamined in light of the demands of the health needs of the heart attack victim. As Mangus has pointed out, "It is believed that the most pressing interpersonal problems in marriage arise out of disparities among the role concepts and self concepts that are pertinent to the marriage situation."[45] It is plausible to think that the conflict which studies[46,47] have indicated in a common accompaniment to rehabilitation in the home is linked to changes in patterns of role expectation, self concept, and role performance.

The demands of the illness and recovery periods may cause members' personal goals to have to be held in abeyance for a period of time, and may even be perceived as no longer viable. Conditions which give rise to discrepancy between members' goals and the goals they perceive the family as being able to satisfy can have an alienating effect in the family. Rosenstock and Kutner describing one form that alienation might take - retreatism - suggest that, "This may involve the voluntary or involuntary separation of alienated members from one another or from the rest of the family, or the social and psychological withdrawal of such members even though they are physically present."[48]

What is being suggested is that the recovery process from illness can, and often does, create the need for a reordering of family roles and priorities, and that this can result in feelings of social and psychological loss in certain individuals with the result being a weakening of the family bond. However, it is also reasonable to expect that the reordering of the family lifestyle can be experienced as social and psychological gain for some members. This could occur when members, who prior to the illness felt themselves alienated, or at odds with some aspect of family life, now perceived the family as changing in a way favorable to their personal goals.

It is an aim of this study, therefore, to identify the conditions under which members of a family will experience the home care phase of recovery from a serious illness like heart attack as threatening to their interests, <u>or</u> as an opportunity to improve their chances for a more rewarding personal and family life.

This will lead to another issue. It is reasonable to expect that people will generally try to minimize the threat to their psychological and social well-being, and maximize opportunities for stable, fulfilling relationships. I will explore the proposition, therefore, that the way the recovery process is perceived and organized in families reflects the desire to either stabilize family relationships which show signs of deteriorating under the stress of illness, or to bring about changes in basic family patterns which some members feel are needed to correct an imbalance between family goals and family routines which preexisted the illness onset.

The desire that the recovery process be compatible with highly valued personal and family goals may conflict with definitions of the situation held by medical professionals involved in the patient's care, or with obligations members themselves feel they have in representing the medical system's perspective in the home. The tensions engendered by such a conflict may well be an important source of personal and group discontent. However, such a set of circumstances may lead members to redefine the situation by reformulating rehabilitation priorities, and reinterpreting the health needs of the member-patient. Cowie reports that it is common practice for recovering heart patients to "rewrite the past to fit the present."[49] What appears to be involved is an attempt to re-explain events which occur early in the patient career to enhance a return to a normal lifestyle unencumbered by fears of illness reoccurance. Davis found a similar process of continuing review and reinterpretation of the illness in families coping with polio. He observed that in spite of obvious and abrupt changes occasional in family life by the child's handicap, "...it was remarkable how little conscious or explicit awareness of such changes the families demonstrated." He goes on to point out, "The social scientist cannot help but point to the many positive social functions served by so steadfast a continuity of identity. Among other things, it helps to move persons and groups psychologically in ways to inure them to the potentially too disruptive effects of change."[50]

This present study did not begin by formulating hypotheses as to the relationship between family structure and response to illness crisis, nor were predictions made with regard to how families would interpret and consequently carry out the management of the patient's recovery from illness. Yet it was my operating assumption that variations in coping would be associated with patterned differences in family structure and culture. Within my group of eight families there were sharp differences in family organization and in the requirements for maintaining family cohesion and integration. Comparing the way of life in each family allowed me to discover that where family members valued a role-exchange type of division of labor there were important sources of social support outside the family. In contrast, where a role differentiated division of labor was valued, the nuclear unit far surpassed any external group for providing social and psychological support. Another way of putting it is to say that when family members valued joint participation in the external community and close companionship in the home, they arranged their internal affairs so that the actions of every member would be systematically coordinated with all the others. Reciprocity in role obligations provided for interdependence without erasing distinctions based on sex and generation. In contrast, when family members valued separate participation in the external community, and separateness in the home, they arranged their internal affairs so that members would not be highly dependent on one another, and could arrange their family obligations to fit the demands of their personal commitments to external groups and interests. This prevented conflict from developing between family and outside.

For the role-exchange, low companionship family members, the problem after hospital discharge centered around how to provide for the patient's day-to-day care needs and make the necessary adjustments to keep the home functioning smoothly, while still maintaining independence with regard to personal activity at home. Moreover, how could the home care be managed without placing heavy demands on members' time and, consequently, compromising members outside interests? It was obvious to the role-exchange family members that the patient at home was limited in his ability to carry out normal functions or to provide for himself the services which he needed. Yet, if the wife or children attempted to exert direct control over the recovering patient's activities, they would be behaving in an unaccustomed manner which was at odds with what was normally preferred. A particularly difficult issue to be grappled with was how to respond when the self-initiated actions of a husband-patient seemed, in the opinion of the others, to be dangerous in view of his fragile health. Family norms usually dictated a policy of non-inteference; but now members would also feel some sense of obligation to make the ill person avoid situations which could cause him reinjury.

It seems apparent, therefore, that situations in which the family members felt constrained to become directly involved with the patient for any extended period of time would create uncertainty, and could lead to conflict. The more frequently such situations arose, the greater the chance of unanticipated hostility. In addition, if the situation demanded too extensive an involvement at home by members who preferred outside activities, the conditions precipitating alienation would be created: personal goals would clash with the exigencies of the situation.

One could argue, on this basis, that members of role-exchange, low companionship families would seek the early withdrawal of the heart attack victim from a patient role, and a rapid recovery of normal, pre-illness role functioning for everyone. Consequently, it can be hypothesized that over time these members would increasingly incline towards perceiving the positive aspects of the patient's condition, and emphasize what he was able to do, rather than what he was unable to do. It can also be hypothesized that if the patient's condition worsened over time, interpersonal relationships would be placed under increasingly greater strain.

For the role-differentiated, high companionship family members, the problem after hospital discharge centered around the need to redistribute role functions. While the form of family relationships in the recovery process might continue to follow a role-differentiated style (with the husband playing a patient role to the wife and childrens' nurse-surrogate role), the content of role functions would change in ways which could appear incompatible with idealized definitions of self, and/or incongruous with behavior expected of husband, wife, and child.[51] Natural coalitions within the family might be altered since children and the mother might be expected to team up to induce the patient to conform with the medical regimen as it is perceived by them. This could bring about personal and interpersonal stress since members, especially children, would feel ambivalent about changing loyalties even as they feel obliged to while the father is in the recovery period.[52]

The tensions engendered by this situation could be expected to last as long as the role-differentiated wife felt the husband-patient's health obliged her to organize and implement the management of the home care.

The added control over family activities which might accrue to wives who valued role-differentiation and companionship could also bring them certain advantages. As I pointed out in describing family lifestyles, these persons had a high stake in the family because for them it was the primary source of social and emotional satisfaction. It can be postulated, therefore, that the wives might be constrained to use their influence in the recovery process to bring about more general changes in the family, specifically ones which would bring her spouse's behavior more in line with her expectations.[53] The illness might be used as a way of enhancing her power to control family affairs and create a more favorable climate for her own self actualization.

The probability of this occuring might be expected to be especially high in families which prior to the illness there had been major discrepancies in role expectations and role behavior.

One could argue, on this basis, that wives who valued role-differentiation would oppose the early withdrawal of the husbands from patient roles, and themselves from nurse-surrogate roles. It can be hypothesized that these members would incline toward perceiving the negative aspects of the patients' condition, and emphasize what had to be done for them and what the men could not do, rather than what they could do.

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Chapter 5

Perspectives on Home Recovery: Reordering Roles and Priorities

I. Transferring Responsibility from Hospital to Home

The passage of the patient from the hospital ward to the familiar surroundings of home might be expected to be a time of relief and celebration in the family. Davis reported that when the day of homecoming finally arrived for the families he studied, "A reunion glow suffused the life of the family; doubts were temporarily laid aside, and a determined effort was made to 'look on the bright side of things.'"[1] This was not the case for the families I studied. Upon the arrival of the heart patient home from the hospital, the atmosphere in each of the eight families was suffused with worried concern. The patient's removal from direct medical supervision seemed to cause the family members a high degree of apprehension over whether he could be safe with only his family to look after him.

The day of homecoming set the tone for the days, and in the case of some families the weeks, which were to follow. There were no celebrations or ritual events to mark the passage from hospital to home, or to give any indication that a new status for the husband-patient had been achieved. By everyone's account the men appeared reluctant to explore the home they had been absent from for several weeks, and their families urged them to spend the day in bed, or at least to sit reading or watching television. Not only were there no celebrations, but also there was a deliberate attempt to transform the home into a quiet, restful place for the sick. This pattern was the same in all families but one. Against his wife's strenuous objections, Mr. Polski insisted on accompanying her to the store where he waited in the car while she shopped. However, he later admitted that he should not have gone since he became very tired. For the rest of the day, and for the next several days, his behavior was very much like that of the other men: he remained almost exclusively in bed or in a chair.

On the basis of what I was told by family members, and what I personally observed in the first two weeks following hospital discharge, it seems reasonable to characterize this period as <u>The Period of Extension of Hospitalization</u>. In response to the anxiety generated by the homecoming, particularly around the issue of preventing any circumstances from arising which would cause the men to be placed under physical or mental stress, wives, children, and the patient-husbands themselves tried to incorporate into the home atmosphere the safeguards they had witnessed - and felt secure in - in the hospital, especially those of the Intensive Care Unit. This included the men assuming patient role typical of acute illness, with wives and children acting the part of nurse-surrogates. These roles emphasized passivity and inactivity for the husband

and close surveillance by his wife and children. One of the major characteristic features of the <u>Period of Extension of Hospitalization</u> was that the men at home were all less active than they had been in their final days in the hospital. In terms of willingness to test themselves by walking or lifting small objects, which most men had done in the hospital, their present reluctance to do much more than sit or sleep represents a regression to earlier stage of illness.

Each of the wives I spoke with about this period believed that she had an important but difficult responsibility: making the home environment as safe as possible for the husband-patient. Practically speaking, this included preventing any but the most necessary activity on the man's part, discouraging visitors, keeping strict control over food preparation, and protecting him from situations which might cause any anxiety. Wives were particularly careful that household chores were taken care of so he "won't worry about it." One of the sources of the wife's sense of obligation for the husband-patient's safety, and consequently of her willingness to work so hard, was the fear that his health was so fragile that it was subject to sudden renewed reinjury with little provocation. Moreover, the family had observed in the hospital that the patient tended to do too much, according to its perception of his care needs. Wives and children believed that their role was to continue the function of protecting the patient from the environment, and, very importantly, from his own acts.

Wives and children watched the husband-patients, as they had been constantly monitored and observed in the ICU, and they tried to keep them immobile. One husband said: "If I drop a piece of paper, she won't let me pick it up." I asked another: "Are you both in agreement on the amount of activity you should be getting?" He answered: "Oh yeah. She is right on my tail - don't, don't do it." Just as the ICU nurses told them not to do anything without being assisted and to let the nurses take care of their needs, the wives also expected their husbands to rely on them. Mrs. Warren said: "If he wants to help me lift anything, I'll say 'No, I'll do it.' He has not gone down the steps to check the water in the boiler yet: I won't let him."

When a man even accidently attempted anything considered potentially dangerous by the wife, he was checked by a sharp word from her. She used the same means to control patient behavior as the ICU nurse had - by reminding him of his susceptibility to reinjury, and demanding compliance.

The fears of the wives at this time were dramatically conveyed in stories I was told by a number of them relating incidents in which relatives or neighbors had died of heart attacks suddenly, even "right outside of the doctors office", or, "just as he came home from the doctor." These fears were probably behind the lengths to which wives went in order to monitor and supervise the men's activities. Those women who had jobs stayed home, at least for the first several days.

All altered their normal schedules to be in the home, even in the same room as the sick person.

These stories of sudden death were in many respects like the ones told to me by ICU nurses of patients who died on the ward following exertion. The similarity suggests that nurses responsible for new heart patients, and wives in their role of nurse-surrogate who feel responsible for newly discharged heart patients share a common set of problems. Both are cognizant of the limitations of medical science to cure the illness. The stories told by nurses and wives all stress that patients died in or near a medical setting, and with little forewarning. Both nurse and wife worried that even the well-intentioned patient was capable of dangerous overactivity, and both felt accountable for preventing situations from arising which might threaten the patient's chances for survival. By "doing everything possible" to counteract any attempt by the patient to be autonomous or active, the care givers shield themselves from the possibility of guilt or blame in the event of death.

The enforcement of extensive limitations of activity may be seen as a way of adapting to the high degree of uncertainty of the situation. The ritualistic application of a set of controls which in its rigidity went beyond what was required by medical guidelines may also be conceived of as a functional equivalent of magic[2]. As Parsons explains, "The basic function of magic... is to bolster the self confidence of actors in situations where energy and skill _do_ make a difference but where because of uncertainty factors, outcomes cannot be guaranteed."[3] The wives believed they would have much to do with the quality of the husband-patient's health once they left the hospital. They were highly involved emotionally. Yet, they were uncertain whether the goals to which they were committed were achievable in the home setting. Their actions seemed to be an attempt to re-create the safe atmosphere of the ICU. By precisely following what they had seen done by ICU nurses, the wives hoped to stand between the men and disaster. Not only was it hoped that this highly restrictive approach would offer more certainty that the patient would suffer no harm, but it reduced the amount of individual judgement required.

Another characteristic of the Period of Extension of Hospitalization was the absence of open interpersonal conflict in the families. Couples who regularly argued before the illness seemed to be in accord during this period. When a wife became upset because the man did not want to take another nap, or when she noticed him doing something like putting a dinner plate into the sink, it seemed like a word from her was usually sufficient to cause him to comply with what he was told. Children also were more likely to offer to help their mother, and in the case of the Asti children there was a moratorium on arguing. Rose Asti said she could not remember a time when she and her brother John got along so well.

At this point, one could argue that the family members perceived the crisis as having been imposed on the family by forces outside the control of anyone in the group. No one, therefore, could be blamed for the troubles the family was having. Responding to an external threat seemed to heighten the members sense of loyalty to one another and, consequently, affective interpersonal relations strengthened the integrity of the family bond.[4]

In contrast to the harmony between individuals, they shared an acute sense of fear and doubt about the illness reoccurring. This was reinforced whenever the man felt even slight discomfort.

From the comments made by family members during this time, it is apparent that a small amount of chest pain which might be expected to occasionally arise in any recovering heart patient, and for which several patients had received medication (nitroglycerine), was enough to reaffirm the family resolve to prevent any unnecessary patient activity. Not only chest pain, but any sign that the patient-husband was unwell was cause for continuing alarm. Mrs. Asti was concerned because her husband's feet were cold at night. She said they never were before. To her, this was indicative of the man's fragile state of health. Mr. and Mrs. Goldberg's reaction was not untypical. My statement, "I guess it's nice to have your husband home," led Mrs. Goldberg to make the following comments:

> Yes, but it's very worrisome. It's very uncertain. I'm very frightened, let me put it that way... Last night he said he wasn't feeling that good, and it's very upsetting. You wonder: What's going to happen now.... I told him: 'Why fight it. Go to bed'.. I didn't know how bad he felt. He said this morning, 'Gee, I didn't think I'd make it.' I don't know if he was exaggerating or whether he was scared. He (said he had) a slight pain up here. It's not all healed.

On another occasion, a complaint of a slight pain made Mrs. Goldberg feel ill herself. Another wife, Mrs. Ambrosio, said that when she held her husband in bed she could feel that "his heart was irregular" and she wept.

For Mr. O'Shea the days following hospital discharge were "worse than when I went into the hospital." He said he felt "run down, and washed out." When I asked why he didn't feel "washed out" in the hospital he replied that then "something's going on all the time. I wasn't by myself thinking, thinking." One of the things he was thinking about was whether he was doing what his doctor advised. Before he left the hospital he was told "not to tire myself." He was also told to nap during the day. However, Mr. O'Shea found himself unable to nap - "my mind keeps active" - and by nightfall he would feel fatigued. This led him to worry whether he was getting worse, which was on his mind when he tried to nap. To compensate for his inability to nap he tried to remain sedentary and when I asked him to compare the amount of activity, including walking, he had now with what he had in the hospital, he replied that he did more in the hospital.

The recovering men, and their families displayed a high need for reassurance that healing was taking place. They were impatient for the first visit with a doctor, particularly a heart specialist. At the end of this chapter I will take up the issue of the family's concern that the family physician was not qualified to handle the heart patient's needs. For now, I merely want to point out that the time between hospital discharge and the first doctor's visit was experienced by the family in such a way as to heighten the anxiety and to increase their dependency on the health care system.

Waiting to be seen by the doctor was, as Mrs. Goldberg put it "like waiting for the Lord." I happened to be present when Mr. Ambrosio received in the mail his appointment slip for the first post-hospital electrocardiogram. His reaction was a combination of relief, and jubilation.

At the outset of home care, patients and family members waited anxiously for the medical care system to resume direct control over patient management. Given the doubts and fears they labored under, two or three weeks appeared to the family members as a terribly long time to have to wait to learn if the man had improved or gotten worse. For some people it seemed as if they had been abandoned. Mr. Ambrosio expressed this sentiment to me in the following way.

> I think it is a glaring fault of the system. I'm home now roughly ten days and no one has called from the hospital; neither social service or medical to see how I'm feeling.... While you

> are in there (the hospital) you get all this positive approach. Everyone is trying to help you: Do this, do that, get your food, get rest and all that. Then when you get home....

Mr. O'Shea called the hospital for help in getting a prescription for medication filled. He was discharged from the hospital on New Year's day and could not find a drug store open. The following day his family was in a state of panic, because the local pharmacist told them he thought this particular drug had been discontinued, Mr. O'Shea recalled these events:

> I was without (the medication) over a day already. I was starting to sweat it out and finally I says 'let me get in touch with the hospital and see what goes on.' I asked for Dr. A.... I says to him: 'How's the chance of getting (the medication) in the pharmacy there?' He said, 'I don't think they fill prescriptions there for people not in the hospital.' Finally, that day about 5:30 P.M., the druggist found it and sent it over. That was quite a relief.... It shook me up something terrible. I don't think I recovered from that yet.

A problem which several families faced during the early days of the home care was how to manage the diet. At least three families believed they were supposed to follow a diet regimen but were given no written instructions. Mrs. Goldberg said she was told, "since he's an old diabetic just feed him like before." However, she told me, "we've gotten away from his diet for a long time now so I really don't know what to feed him." Mrs. Asti thought her husband was told to follow a low caloric diet. She did not quite know what this meant.

Since the first appointment with the doctor was two weeks away she tried to remember what her husband had been fed in the hospital. Her uncertainty over the adequacy of the food she was preparing caused her considerable upset. She was very impatient for the opportunity to discuss this with the doctor. The Warren's did receive written instructions concerning the diet regimen on the day Mr. Warren left the hospital. However, in my first visit with the family shortly after homecoming both spouses reported that it was complex and ambiguous. They hoped that I could help them clarify what the instructions meant precisely, because they felt at a loss to do so themselves.

Doubts about the diet again made the hospital care the model to follow at home. Until they could see the doctor, they would be as cautious as possible, and the members searched their memories for what they had seen while in the hospital.

The start of the home care phase of recovery from heart attack seems to contain a number of elements which operate to <u>increase</u> the patient's and the family's <u>dependency</u> on the health care system. Consequently, progress toward rehabilitation comes to a halt and even regresses for a period following hospital discharge. Without the presence of medical experts to direct and reassure him, the heart patient at home can become immobilized. Moreover, while the family members were actively involved in patient care at home, their actions were directed toward maintaining a hospital-like atmosphere resulting in a parody of the ICU. Every attempt was made not to develop autonomous rehabilitation roles, but to enforce a pattern of behavior appropriate for patients in an acute state of illness.

The reaction following hospital discharge parallels that which some of the men experienced when they were transferred from the ICU to the general medical ward. Then, the reduction of direct professional supervision also caused several men to seek security in highly sedentary behavior. Recall also that the transfer heightened the worry of the family members with the result that many of them tried to compensate by protecting the men from activity themselves. At each point when the setting of care seemed to provide the opportunity for greater patient-family autonomy, the result was more, not less, dependence on restrictions, and commitment to the passive-dependent sick role. At least at the outset of home care, all patients and wives and children were fearful of dread consequences of the illness. For a short time, all the patients acted like "cardiac cripples"[5] in that their fear of reinjury prevented them from behaving up to their potential.

When one examines studies which have attempted to identify social psychological factors conducive to favorable recovery of social functioning following heart attack, the dangers posed by not preparing the family for home care become apparent. Wrzesniewski[6] has found that the type of attitude least favorable for rehabilitation is one in which anxiety predominates, the demand for medical care is high, the mood is low, and the level of fear of the illness is high. Garrity[7] has linked a delayed return to work following myocardial infarction to a pessimistic view of health held by the victim and his significant others. Rosenbaum and Belknap[8] have argued that "the fear of heart disease and of its dread consequences, thoughtlessly inspired by the attending physician and carefully nurtured by the patient, his wife and his children, is the important cause of the proclaimed disability and of the unnecessarily enforced illness." [9]

According to the observations made of eight families, one is able to note that unless the patient and his family are ready to assume the responsibility for care, there is the danger that the withdrawal of medical support will be perceived by them as threatening to the patient's well being, and will cause the family to try to compensate for it by adopting a highly conservative stance toward treatment, a negative outlook for the future, and an inflated view of their need for continuous medical attention. One cannot help but note, however, that such consequences as these seem inevitable given the suddenness with which the transition from hospital to home took place.

When the care system discharged the patient from the hospital, it left the family on its own. Preparing the family for home care with a few general guidelines and advising that a physician's appointment be made in two or three weeks, the care system left the patient and his spouse to grapple with the day-to-day complexities of the care alone. It provided no mechanisms for linking the family with the care system, at least until the first visit to the physician. Decisions with regard to helping the patient, or adjustments to slight but worrisome changes in the way the patient was feeling were placed entirely on the family. The care system acted as if the patient and family were able to be self-reliant without any preparation. As a consequence, there was no way of knowing whether the actions which the family was taking at home were confluent with the expectations of the medical care system.

II. Problems of Role Complementarity

In the period I have just described, The Period of Extension of Hospitalization, I noted that there was little tendency for the family members to engage together in discussions of patient activity. Questions of what the patient could and could not do rarely came up. The patient simply did as little as possible. As Mr. Ambrosio put it, "When in doubt, do nothing." Everyone ascribed to this orientation.

Agreement over the means of coping with the management of the recovery process which characterized the early days of home care, began to come apart as soon as the husband-patients made their first tentative moves toward activity in the home. Six of the men decided to increase their activities before seeing their physicians and without the guidance of their wives. First, they seemed to test themselves by walking around the home. Gradually they began to do things like cleaning the dinner dishes, or setting the dinner table, changing light bulbs, and the like. When they discovered they could accomplish these activities without discomfort, they attempted slightly more substantial tasks, for example, carrying a bag of garbage from the kitchen to a pail in the pantry.

There was a tendency for the men to choose as their first significant task something which prior to the illness they usually did as part of their regular household duties. Two men went down to the basement to check the heating system. One of them, Mr. Stein, told me that even though he realized that his wife had been handling this chore successfully in his absence, he felt he had to check it for himself. "I must see that you are doing it right," he said to his wife when she objected to his going down the stairs. Mr. Ambrosio felt he had to check a small crack in his basement wall to determine if it needed repair. With this goal in mind he went down a flight of steps for the first time. Again, this was done over his wife's objections.

At the time the men began to slowly test what they could do, they also took steps to be less visible to their spouses, who were inclined to oppose non-sedentary behavior. The first few days at home when the men were not in bed, they usually stayed in places where they could easily be observed - the kitchen or the living room. This space in most homes is the domain of the wife, and where she usually does a large share of her housework. Under this arrangement, the wife could continue to do chores and watch over her husband. As Goffman[10] points out, different spacial settings of social establishments have their own unique norms of decorum. In many homes, the living room is set aside as a place of rest. As such the husband-patient's presence there might have symbolized his need for a protective environment which contained built in constraints against activity. Given the fact that some homes had dens, finished basements, and attached work rooms, where the men might have chosen to spend their time, the choice of the living room as the major place of rest seems to have been made purposefully.

Once a man opted to become active, he changed his location within the home. For example, when he rested, Mr. Ambrosio chose the den where he had a desk, and which was situated near the front door. He could bring in the mail and newspaper before his wife knew they had arrived. Seated at the front window he could greet his neighbors as they came home from work. He also could look out over his garden and mentally prepare his spring planting. Mr. Stein likewise relocated to a corner off the kitchen where he stored the material he used to make stock market calculations. When he first came home, he had stayed in the living room. When Mr. Polski decided that the time had come to become more active, he left his home in the city for the country place which was in the final stages of construction. This provided him with ready access to numerous small chores. It would appear that there were practical and symbolic aspects to these spacial relocations.

These beginning steps toward activity marked the start of rehabilitation. They also radically altered the social and emotional climate in the homes. The wives all strenuously objected to the men assuming even minor roles in the housekeeping. For the first time since prior to the illness, family conflict erupted. The issue which was thrust to the fore was: whose role was it to decide what activities were permitted; who had the major responsibility for directing the course of patient care at home?

The wives and children generally agreed that the men were now displaying the same lack of judgement they had exhibited in the hospital. They were both frightened and angry. The wives went to considerable lengths to halt the trend toward activity. When any of the men went beyond the bounds of safety drawn by the wives, the response of each of the women was uncharacteristically forceful. Mrs. Stein, who normally preferred to be noninvolved in her husband's affairs, described herself as "hysterical" and "shrill" when she learned that her husband had smoked a cigarette. When she discovered that he stood on a chair to change a light bulb in the kitchen during her absence, she "hit the ceiling," and demanded that he not do such a thing in the future. Women ran after their men and tried to stop them when they tried to carry out the garbage, or to walk out of doors. Mrs. Ambrosio even threatened to hit her husband if he did not reduce his activities.

The wives still considered the men very sick, and under the current norms, not supposed to take independent actions. From this viewpoint the wives felt they had an obligation to step in and stop it. However, from the perspective of the husband, his activities reflected his decision that could safely step out of the rigid guidelines he had been following since coming home from the hospital. Even men who were not fully confident in this decision decided it was time to test their stamina. Mr. Asti was not certain what he was allowed to do at home in any specific terms, and in the past had shown a tendency toward inaction. Yet, he felt after about a week, "You just can't sit around for the rest of your life. I would not want to sit around for three months and all of a sudden start to move around. I don't believe that the doctors mean for you to do that anyway. They would rather see you move around gradually. That's my feeling on it anyway." The wife of another patient, Mrs. Ambrosio, described the early steps away from inactivity this way: "The things he is doing, it is just to do something. Doing the dishes, and I notice how he is eating. He used to be more relaxed... now he is eating and doesn't know what he is eating. I think he is very tense. He gets up and tries to do the dishes right away. He wants to do something, keep doing."

For the first time different perspectives on the nature of the illness and the requirements of care and treatment brought forth a confrontation between the spouses. In the hospital, different viewpoints existed but were not openly acknowledged. Patients and wives were not totally unaware that they held discrepant definitions of the situation, but the extent or basis of the differences were never explored.

The conflict over the activity of the husband-patient may be conceived of as a struggle between conflicting claims to legitimacy in representing the medical point of view in the home. Each spouse felt more equipped than his or her partner to decide how best to give specific meaning in everyday terms to what the physician or nurse had said about "taking it easy." The husband-patients argued that their wives interpreted the medical regimen too strictly, while the wives felt they were morally obliged to prevent the men from engaging in what they perceived as potentially harmful behavior.

In pressing their respective claims for control of decision-making with regard to patient care, the spouses faced certain dilemmas. The wives saw themselves as essential to the preservation of the hospital-like atmosphere. They felt they could not simply withdraw from their role as medical surrogate. However, continuing to insist that the men act as if they were still acutely ill brought with it the very real possibility of conflict. This, in itself, would disturb the restful atmosphere of the home. For their part, the husbands had no way to demonstrate that they could safely perform the activities they were now proposing to do, and were not merely disobeying medical advice. There were no visible signs marking the transition from one state of health to another. They had no proof they were fit to leave the sick-role for one more compatible with rehabilitation. This is the reverse of a problem chronically ill patients in a later stage sometimes experience, that is, convincing persons unfamiliar with their condition, that they actually have a disabling condition - like heart disease - which while it does not show prevents them from full role participation.[11]

In contrast to the earlier perception within the families that their troubles emanated from external sources, the present difficulties were seen to be directly related to ill-advised behavior of individuals inside the family. Thus, rather than closing ranks against an outside threat, the family members struggled with one another. The result was to decrease family harmony and pose a challenge to the solidarity of the group.[12]

If one looks at the problems these eight families faced following heart attack in terms of the quality of interpersonal relationships, the first point of stress seemed to come not immediately after the onset of the crisis but weeks later when family troubles were defined as internally generated. The more immediate effects of the onset of the illness increased family solidarity.

III. Family Structure and Patterns of Rehabilitation Role Organization

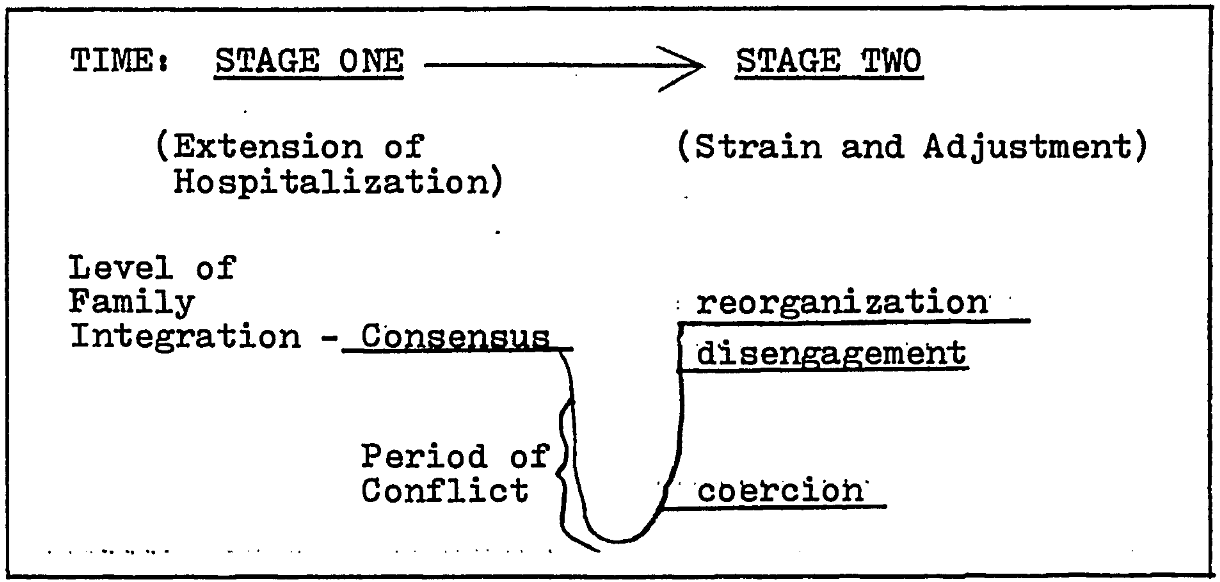
Conflict generated by discrepant expectations with regard to home care role performance was a problem each of the families had to deal with shortly after the end of the Period of Extension of Hospitalization. While the source of family interpersonal strain was similar in each case, the ways of problem solving varied. Problem solving seemed to be influenced by important group values. Since the nature of the problems to be faced now raised serious questions among the members about the manner in which they had been managing the recovery process and posed a direct threat to the stability of the family system, I am calling this stage in family response to illness: The Early Period of Stress and Adjustment.

Adaptation to the current period of stress took three forms.

1. Coercion: Here family members attempted in various ways to force the husband-patient into compliance with the definition of the situation held by the wife and children.
2. Disengagement: Here, the strategy was to allow each person a share in decision-making responsibility with no one person monopolizing the management of the home care.
3. Reorganization: Families in this case reached a mutually acceptable understanding that the wife would retain the major input into the organization of the recovery process.

Each mode of adaptation had a specific effect on the affective climate in the home. This outcome can be schematically represented in the following way:

FIGURE 1*



* Variation on R. Hill 1958[13]

Where coercion was the means used to settle differences with regard to home care behavior, affective relations between the husband-patient and others who now were his adversaries were marked by frequent hostility and antagonism. As defined by Spiegel, coercion involves "manipulation of present and future punishments. Thus it ranges from overt attack to threats of attack in the future, and from verbal commands to physical force... If it is successful, the role conflict is settled through submission in which ego accepts the complimentary role enforced by alter."[14] By attempting to coerce the husband into submitting to a role of seriously ill patient two negative consequences for the family sometimes surfaced: When the husband defied the others, conflict ensued; when he did submit the result produced alienation - the individual perceived that the family no longer fulfilled his goals or provided the outcomes he valued.[15]

Where family members choose to <u>disengage</u> from tenaciously held role definitions, each party accepted somewhat less autonomy than he or she expected at the outset of rehabilitation. Something like Spiegel's concept "role reversal" seemed to apply whereby "ego proposes that alter put himself in ego's shoes, trying to see things through his eyes."[16] Insofar as this was a pragmatic attempt to stabilize relationships which had become conflict ridden due to discordant role expectations, the result was partially successful. However, stress was still present because each person was behaving in less than complete harmony with his or her expectations.

Families in which role conflict led to a mutually acceptable change in normative role behavior (reorganization) experienced a heightened sense of togetherness. Reequilibration was accomplished through a change in roles for both ego and alter. Spiegel uses the term "role modification" for this situation, meaning that "the change in role expectations is bilateral, and modification techniques are based on interchanges and mutual identifications of ego with alter."[17] In this case, the wife was able to fully actualize her expectations with regard to her and her husband's home care role behavior.

These were highly compatible with those she valued prior to the illness. Moreover, the husband, in this stage of his patient career, seemed willing and able to be convinced that he needed his wife to play a strong nurse-surrogate role, and postpone his aspirations for an increased level of self-initiated activities.

Parad and Caplan have emphasized that, "When the family faces a stressful event, its lifestyle (values, division of labor, and communication patterns) places at its disposal a range of problem solving possibilities..."[18] It seems reasonable to expect, therefore, that family structure and value climate might predict the response to the role conflict the family now faced.

The families adapted in the following way:

FIGURE 2

FAMILY TYPE	MODE OF ADJUSTMENT
Role Differentiated - High Companionship	Coercion
Role Exchange - Low Companionship	Disengagement
Role - Companionship Dissensus	Reorganization

IV. Home Care Role Adjustment in Role Exchange - Low Companionship Families: Disengagement

The Role Exchange - Low Companionship Families were: the Polski's, Stein's, Asti's, Warren's.

As mentioned, overt conflict between spouses erupted when the husband-patients began to engage in what the wives considered unnecessary walking, and other activities around the house. For several days, tension and hostility reflected the division in the attidues of the spouses toward rehabilitation priorities. Each partner at first seemed firm in his or her conviction. Wives tried to impose on the men rigid guidelines which called for a highly sedentary routine. Husbands insisted on the right to choose the level of activities they believed to be appropriate for their conditions.

The first steps to reduce the hostility were taken by the role-exchange wives. Shortly after the conflict erupted, the wives diminished the level of their opposition to their husband's behavior and disengaged, in part, from the nurse-surrogate role. Each of the four role-exchange wives withdrew her demand that she alone would regulate her husband's behavior. She ceased shouting, and attempted to stop arguing with her husband before the point where it would become a bitter altercation.

Mrs. Stein who had earlier described her response to her husband's behavior as "shrill" and "like a shrew" explained that she could just not cope with the ill feeling generated by her attempts to coerce her husband. Besides, she felt it was having a negative influence on her own physical and emotional health, as well as on the health of her husband. Her husband, Mr. Stein, described the change in her approach: "On certain things I get bawled out. I mean endearingly. She says, 'It's not good for you!'"

In place of strident arguing, the four role-exchange wives all turned to persuasion as a means of getting the husband-patients to do less. For example, on one occasion when Mr. Asti started to descend the basement steps, his wife told him that it was too early in his recovery for him to have this kind of exertion. Once Mr. Asti firmly restated his intention to go to the basement his wife only insisted that he go very slowly, and support himself on the railing. She went with him every step of the way, reminding him to be careful. Mr. Asti's daughter, Rose, explained that her father became angry whenever anyone tried to interfere with his plans. Her response was to be helpful but not interfering. She explained her approach this way: "I would do whatever he asked, but I would not keep asking: 'Do you want this, or this, or this?' I would just do what is necessary."

The wives tried to remain close to their husbands, often suggesting that they rest or postpone some activity until a later time. I asked Mr. Polski, shortly after he and his wife had gone to their country home, how often his wife reminded him to slow down his pace. He replied, "Well, she leaves that up to me. But she's after me. Like I wanted to do a little but this morning she said: 'Don't knock yourself out.' She was after me from three o'clock to knock it off, because the day before I had gotten chest pains."

The wives told me they tried to remain very aware of where their husbands were and what they were doing because they hoped not only to persuade the men to do less, but to actually assist them and thus lessen the burden of activity. Mrs. Polski explained: "Yesterday he was rushing around so much, I swept the basement so he could get done quicker. If he does it, he'll never come up." Mrs. Warren, who before the illness rarely engaged in joint activity with her husband, now sat with him so she could be available to perform small services like turning the TV dial, bringing in the newspaper, getting a cup of tea. She did not want him doing these things himself.

Mrs. Asti learned that while sometimes she could assist her husband with his activities, there was also the chance that her actions would be interpreted as interference and lead to quarreling. Therefore, she began to ask relatives to "drop by" when her husband was planning to make some household repair. Mr. Asti seemed willing to accept help from relatives more readily than from his wife. In order to utilize this strategy most effectively, Mrs. Asti had to follow her husband's activities closely. So while she tried to be non-interfering in his activities, she remained highly aware of his whereabouts, and plans.

In playing a modified nurse-surrogate role, the role-exchange wife was still able to communicate to the man her expectations toward home care behavior. She could not help but be a restraining influence. This was evident when the men agreed to compromise. For example, when a wife suggested that a planned activity should be postponed, he might respond that afterward he would be sure to rest.

In each of the role-exchange families there was evidence that the husband-patients sometimes felt obliged to follow the wives' admonitions. Some men indicated that wifely input could, in some cases, be valuable in preventing them from misjudging their real limitations. Mr. Polski said: "I think it is good to have my wife reminding me of what to do rather than have someone who didn't care. If she didn't, I'd probably be doing something I shouldn't. It's like in the hospital where you have a nurse after you all the time." While the patient-husbands perceived their limitations in a less restrictive fashion than their wives did, they were still convinced they had a serious medical problem. And one which could become dangerously worse if they over-exerted themselves. They were willing to be active, and even test the limits of their present strength, but doubts about their health, and uncertainty about revovery still remained. Prior to his first medical examination since leaving the hospital, Mr. Asti said to me: "I want to ask if there is any difference in my physical being; if I'm doing alright. Am I coming along as expected or not?" When I asked how he thought he was doing at this point he replied: "I have no way of knowing." This was doubtlessly behind his occasional willingness to be persuaded by his wife. When I asked about his decision to go outside the house for the first time he replied: "It looked nice," I stated: "It looked nice on Saturday too." He explained: "My wife didn't want me to do anything. So being the doctor said take it easy, I figured I'd let another week go by before I tried anything else."

In contrast to those occasions when wifely admonition would cause a man to reevaluate his intended behavior from the standpoint of his own safety, there were times when he seemed to agree with her solely out of respect for her feelings. In a number of occasions when I asked for examples of disagreements the men had with their wives over how to interpret the medical regimen, the men would describe occasions on which they started to do some activity but stopped after wives raised objections. When I asked why, they might reply: "Oh, what's the use of arguing," or "I don't know, I just didn't bother." Mr. and Mrs. Warren both told me that because of her persistence she sometimes accomplished tasks he intended to do. Mr. Asti gave me a similar example of this. He related that he agreed to let his wife go to the store for the newspaper while he dried the dishes. Originally, he intended to do both activities.

Willingness to occasionally adhere to the perspective of the wife, along with tolerating her constant advice and admonition, seemed to be the reciprocal response of the husband-patient to his wife's disengagement from actively seeking a controlling nurse-surrogate role in the home care. It recognized the right of the wife to have some input into the recovery process, without controlling it. It gave her a sense of responsibility, and allowed her to feel she was having some success in carrying out her felt obligations to keep the man from hazardous circumstances. Without some input into the home care the wife might have no option but to demand a share in decision making, perhaps resulting in conflict. It also left the patient-husband fairly free to choose when to comply with the wife's interpretation of the medical regimen.

On the other hand, the men could be forceful in rejecting wifely attempts to control their behavior. They only selectively followed their wife's counsel. Concerning his smoking, Mr. Stein demanded that his wife never speak to him about it. He told her that it was something he would handle in his own way. He never attempted to hide the fact of his smoking from her and indulged his need often in her presence. I learned that these men did not pretend to others that they were doing less than they actually were. They retained for themselves the right of ultimate decision making over their activities.

One of the problems with the strategy of disengagement emerged when the wives perceived the men's activity as especially arduous, or when the men had episodes of discomfort in the chest area. This would compel the wives to act forcefully in pressing their opinion on the men; even to the point where conflict ensued. In other words, there were times when the strategy of disengagement seemed, in the wife's view, to be incompatible with the husband's health needs. At these times a more involved role seemed to be required of the wife. Yet the spector of marital conflict made this a difficult choice, as Mrs. Stein's statement clearly demonstrates: "When we get to the doctor at the center, there is a tremendous walk from where he parks the car to the doctor. Will he be able to maneuver that, will he be able to manage it? Should I call in advance and have somebody meet him there with a wheelchair or something? I don't know if he will want that. He's apt to turn around and shoot me... He's apt to blast me with his tongue out of creation."

During the second stage of home care, "The Period of Strain and Adjustment," conflict occasionally arose in each of the four role-exchange families. The precipitating event usually was the man's perception that his wife was unnecessarily interfering in his chosen lifestyle, while the wife was convinced that she had to try to stop potentially dangerous activity. Besides interpersonal conflict, each spouse seemed to be afflicted with stress which was kept personal and was not shared with the other. The husband who felt recurring "pressure in the chest" did not express the depth of his concern to his wife; neither did she usually share with her husband the full extent of her worry. Wives told me that to do so would only upset the men. It also appeared that wives tried to limit their expressions of concern in order to avoid becoming more involved than they already were. Husbands told me that one of their reasons for not sharing feelings of doubt of the "bad news" of chest pain was that the wives would worry and feel constrained to interfere.

Against the remarkable similarities in their ways of handling the immediate post-hospital days and subsequent shifts, there were, of course, individual differences in levels of group tension, conflict and disorganization. Factors associated with them in role exchange-low companionship families were:

1. Perception within the home of the state of the patient-husband's health.
2. The fit between the nurse-like role the wife was able to play and her perception of her husband's need for external control.

If the patient appeared to be showing signs of improving health and was taking some precautions, a small nurse-like role was sufficient for the wife, who, in the normal course of events, was not used to imposing limitations on others in the family. She could also pursue some out-of-the home activities which normally provided important satisfaction in her life. The husband could begin to resume some familiar activities which were important to him, with only occasional objections from his wife. On the other hand declining health, or even lack of perception of improvement, tended to produce marital discord and intrapersonal stress because the wife was not satisfied that her efforts on the patient's behalf were sufficient to produce the desired healthful atmosphere in the home. She felt required to become more involved, and her husband resisted this.

During the Second Stage, the Polski's experienced the least disruption of normal routines, and were able to relate to each other much as they had in the past. After Mr. and Mrs. Polski returned to their country home, he arose before six and was at work in his basement by nine, doing what he described as "light work." This involved cleaning up, sorting his tools, breaking pieces of lumber, etc. He was, however, taking two naps a day, something he seldom did before the illness. But still, he began to experience chest pains. When he did he took a nitroglycerine tablet and stopped working. He told me he attributed the pain to his lack of judgement as to when to stop working, not to any abnormality in the heart itself. In other words, he believed he was progressing normally, and his wife did too. Both thought that the pain merely warned him to stop working - it was not an inherent danger sign in and of itself. Their confidence in his improvement seemed to be justified by his increasing tolerance for work. By the second week he was able to both increase the length of time he could work and was able to do more strenuous labor: He cut his naps down to one and worked until 4:30. On weekends he and his wife began to resume a bit of socializing. On these occasions, he found then that he could violate the dietary requirements without any noticeable aftereffects.

Mrs. Polski continued to remind her husband about the need for caution and restraint, but she did not often feel the need to challenge him, or press her viewpoint against his wishes. She told me that it troubled her when he took nitroglycerine but the pain did not seem to weaken him - in fact, she said he was getting stronger. This tempered her disapproval of his activities. Several times she began telling me of projects she tried to discourage, only to eventually say, "Well, I can see his point too."

Because it was Mrs. Polski's view that her husband's chest pain was the result of the length of time he was working and not the kind of activities, she did not feel she had to be constantly near him trying to stop his activities. She felt she only had to make sure she was around in the middle and late afternoon. At other times she made occasional checks. This left her free more than any other role exchange wife to pursue her own activities. I asked her, "How about yourself, are you as busy as you normally are?" Mrs. Polski replied, "Oh yes, I don't know where the day goes - I can't understand how some women can say they are lonesome, or they are bored. I could never say that. I can't seem to catch up. I have so much to do. I'm either knitting something or fixing something. The day is not long enough to accomplish what I want. My husband is the same way. The days go so fast." (E.S.) "Is your routine the same or different than before your husband became ill?" (Mrs. Polski) "The same. It is just the same."

Even the fact that she was not taking her normal trips into the city to visit her friends and go to club meetings did not seem to cause her very much disappointment. She accepted this limitation of her freedom as part of her obligation to her husband during his recovery. She felt she had a role to play in reminding him to be cautious and in helping him with his chores. She anticipated that without her presence, Mr. Polski would tend to do more than he was at present. She felt she had an effective voice in the recovery process.

On each of the dimensions outlined above, the Polski's measured up favorably. Mr. Polski's health was perceived as growing better steadily. In spite of occasional excesses, it seemed to his wife that he did demonstrate a willingness to change normal behavior in favor of more cautious "sick role behavior," which was consonant with his perceived health status. His wife was able to play a nurse role she felt was adequate in view of his needs, and was still able to pursue her own activities.

At the opposite end of the spectrum of response in the Second Stage were the Steins. They experienced intense and sustained interpersonal strain, as well as a good deal of individual emotional stress. Each spouse was disappointed with the role behavior of the other. There were regular arguments which created an atmosphere of hostility in the home. Conflict was ignited easily.

Mr. Stein began to have chest pain soon after returning from the hospital. Pain, sometimes intense, came without exertion; and both partners were, not surprisingly, concerned about this. After several days home he began to violate aspects of the medical regimen. For one thing he resumed smoking and, against his physician's advice, drove to the store to get his cigarettes. He made no attempt to hide this fact from his wife who associated smoking with the heart attack. Mr. Stein, himself, called what he was doing, "my own form of suicide." His wife was bitterly opposed to the smoking and accused him of "driving nails into your coffin." He was the least tolerant of all the patients of a role for his wife in the rehabilitation. Her reaction was one of frustration at not being able to control events she felt his health required. She knew that the cost of taking an affirmative position meant conflict, yet she felt she should be involved. Her wariness about offending him did not, however, end the arguments, because sometimes she felt she had to try to influence his behavior. She told me that more than ever before they were quarelling and shouting at each other.

A factor behind Mr. Stein's acceptance of only a minimal nurse role for his wife was that he believed she did not have proper judgment to make decisions for him. She made what he called "bad judgment mistakes." Examples he gave of this included her inviting groups of relatives to visit when he was not feeling well; not screening people from visiting who were usually upsetting to him; and encouraging him to eat more than he wanted to with the result that he once became ill. Her lack of adequacy in the area of food preparation was also a source of strain. Prior to his illness her poor cooking skills was "a laughing matter." Now Mr. Stein resented it because the diet was the part of the regimen he valued most. His wife remarked on this problem: "Now when I come home I get arguments from him: 'What supper are you going to ruin tonight? What are you going to feed me tonight that I am not going to like? What chemicals are you going to give me tonight?' I never had that with him before." Mr. Stein began to seek out information himself on matters such as vitamins, substitutes for what was restricted in his diet, and good recipes for cooking the bland food he was now required to eat. He believed that these were important matters but the couple did not share them together.

Mrs. Stein seemed to be aware of her husband's perception that she was uninformed, and lacking in skills needed during the home care. She admitted to me that she knew very little of what the care required. She blamed this on the medical staff at the hospital who she felt did not prepare her:

> I haven't been told a thing about what to expect: physically, sexually, or brainwise. On TV it said that sex is the best thing after a heart attack. How do I know that's so? Suppose he gets an attack when we are having relations? What then?... I don't even know who his doctor is that took care of him in the hospital. (E.S.: 'What gives you the idea that he can't for example walk out on the porch and take the air?') I don't know. I have no idea. (Yet she was opposed to this activity.) (E.S.: 'Is it possible that going up and fixing that is really OK? I'm not saying that it is, just asking the question.') I don't know...He was told that he has to rest until the scar heals. After that he can go about his business.

The experience of adjusting to home care had the effect of pulling the couple apart emotionally. What seemed especially upsetting to the wife was that for the first week after hospital discharge life had been pleasant. Then, in spite of her lack of knowledge of the details of the case, encouraging him toward inaction was not resented, and it worked. Two weeks later, these same measures on her part brought conflict.

Mr. Stein had a series of upsetting experiences: pain, fevers, flu symptoms. He was depressed and concerned. Yet, he tried to stay involved in his hobbies, and do some chores around the house. "I don't want them thinking of me as an invalid." he declared in reference to his wife and married daughter. "I'm taking a positive approach. I'm looking ahead to getting back to work." At worst, he looked upon his wife's attempts to play a nurse role as detrimental on his recovery. Most of the time he just thought she could not contribute much. I asked him: "How much is your wife involved in your activities at home?" He replied: "What can she do?" Then he said that he did want her to tell him when she saw him doing something that was dangerous to his health. But he could give no examples of this happening; on the contrary, he indicated that he displayed low tolerance for any nurse role on her part.

The state of the relationship was influenced by the negative perception of the man's health; and then the inability of the wife to play a significant nurse role.

The experience of the Asti family in coping with home care adjustments fell between the two that I have just described. The husband-patient did not have chest pain or take nitroglycerine, but he still considered himself in fragile health. He tended to be cautious, and unsure of himself. Yet he was willing to begin some minor activities, even though he worried as he did them. Lack of confidence in his recovery made him tense and unsure of how to go about what he thought was required of him: i.e., gradually increasing activities. He was anxiously awaiting news of his condition.

For weeks, he only attempted to do small chores like drying the dishes, carrying garbage bags to the pail, picking up papers from the yeard. His wife was inclined to try to discourage even most of these activities. He said that he often had to tell her: "I feel alright. I want to do it now. I can't sit down for the rest of my life." He did however, let her help him in some of these activities.

Mrs. Asti had more of a substantial role in managing the convalescence than did either Mrs. Polski or Mrs. Stein. She was completely in charge of the preparation of the food. She claimed that the hospital did not provide her with a diet to follow, so she developed her own set of guidelines, by remembering what he was given to eat in the hospital. Her other resources were her own "weight watchers" diet, and the diabetic diet her own mother had been on. Mr. Asti was not interested in becoming involved in the diet. He seemed satisfied that his wife was handling this alone. In matters related to food, he gave his wife full recognition. For example, he said things like, "My wife is trying to keep me on a low calorie diet as much as possible." Or, "My wife thinks I ought to lose some weight." He also seemed to rely on her to remind him of when to take his medication. Prior to his heart attack, he had been diagnosed as a diabetic, but had stopped taking the medication when he felt better. Now, he was using his wife to insure against this happening again.

It was evident that each of the members of the family were making an effort to avoid confrontation. Rose said she tried to be helpful around the house, and during this time did more chores to help her mother than she normally did. Mrs. Asti appeared adept at knowing when she could express her own opinions about the medical care requirements, and when she should maintain her distance from her husband's affairs. For his part, Mr. Asti tolerated suggestions, and when he did not want interference generally was firm but non-hostile.

Yet occasions when the members clashed could not be avoided completely. Balancing a sense of obligation to have the patient-husband do less with strongly held family norms of noninterference and individual autonomy created tensions in the wife. At times she could not restrain her need to express her views forcefully. She sought support for her position from her daughter. When she complained to her about Mr. Asti, Rose did not agree. It was Rose's opinion that her father should be left to follow his own inclinations. Occasionally this different approach to the problem created heated exchanges of words between mother and daughter.

Aside from occasional episodes of interpersonal conflict, most of the tension was held internally. Neither Mr. or Mrs. Asti was comfortable resuming normal activities, and as a consequence were often in each other's presence. Prior to the illness, Mrs. Asti spent many afternoons with her friends.

Now she mainly stayed at home to be near her husband. Seeing him do more than she thought was wise upset her. Yet she knew that she had to be judicious about expressing opposition to his activities. The novelty of having his actions scrutinized by his wife was something Mr. Asti tolerated but did not enjoy. In spite of being in close proximity for long periods of time, the couple did not seem to develop more of an active companionship.

We saw how the role exchange, low companionship couples tried to reduce the role conflict emanating from differences in perceived means of managing the recovery process by adopting a strategy whereby each partner tolerated the other's perspective. While in most cases the husband seemed able to carry out his inclinations, the smaller amount of influence wielded by the wife enabled her to participate in the recovery process and feel she was having a positive impact even if it was less than she intended to have. As was indicated in the case of the Stein's, however, when the wife perceived that her involvement in her husband's care had no effect on moderating his behavior, the consequences for personal and marital adjustment were severe.

If we examine the adjustments made in the second stage of the home care in the light of pre-illness family patterns, certain explanations for the coping style in role exchange - low companionship family suggest themselves. In role exchange families, individuals expect to have much discretion in the performance of their daily activities. Their organization allows for flexibility in role performance. This seems to be related to the high value role-exchange family members place on separation, as opposed to togetherness, both in activity in the home as well as in activity with external groups and interests.

For a short time after hospital discharge, a role differentiated division of labor prevailed in each role-exchange home. Separation from the hospital temporarily constrained the husband-patients to seek a sense of security in a passive-dependent patient role and encouraged wives and children to assume highly dominant nurse-surrogate roles. However, as soon as the husband regained a sense of security in his surroundings, his preference for deciding for himself what his daily activities should consist of asserted itself. In spite of the wife's belief that he was becoming active prematurely, she did not continue to contest his rightto act autonomously. She continued to give him advice, but withdrew her active oppostion once the man asserted his intension to behave according to his own interpretation of the medical regimen. While the husband-patient insisted on his right to determine his activities for himself, he also recognized the right of his wife to participate in the home care management. In effect, the couple attempted to fit the management of the recovery to the role-exchange formulation: each person participates, neither is excluded, but the norm of noninterference in personal choice necessitates that the husband-patient has the final word in determining his own behavior.

For the wife to have continued to act as if it were her role alone to manage the recovery process, she would have acted in a nonprecedented way given the family's structure and value climate. She would have risked upsetting the basis on which marital stability rested had she tried to impose a role differentiated order in a family which valued role exchange. It was no more in the wife's interest to do this, than it was for the husband. Being a full-time nurse-surrogate would have increased the chances of marital disharmony with no corresponding rewards. In other words, there were no secondary gains to be had for the wife by increasing her control over her husband's behavior. She did not gain by increasing her role in the family, nor did she value the closeness which a husband-patient, wife-nurse relationship would bring. On the contrary, what she valued was her own independence and her own separate lifestyle.

IV. Home Care Adjustment and Role Differentiation

In families where at least the wife valued role differentiation and companionship, the end of "Extension of Hospitalization" did not bring with it a disengagement of the wife from a nurse-like role. Regardless of whether there was consensus on role differentiation and companionship, like the Grasso and Goldberg families, or if only the wife supported this form of family organization, like the Ambrosio and O'Shea families, wives, in this category responded to the husband-patients' attempts to increase autonomous behavior with more, not less, intense and active oppositions of their own. Their efforts withstood a short period of challenge by the men who, for the next six to eight weeks, had their activities supervised and planned by the women. While not always in agreement with the wives, they seemed toaccept the right of the wife to a dominant role in the home care.

In two cases, involving Mr. O'Shea and Mr. Goldberg, the wives had almost no opposition. The men returned home from the hospital very fearful and confused. Mr. O'Shea told me he was better off in the hospital than he was at home and for weeks did little more than sleep or sit by the window in his pajamas. Before either man attempted any activity, he checked with his wife. An active wife-nurse was desired by these two men.

In contrast, Mr. Grasso and Mr. Ambrosio accepted control of their behavior by others in the family less willingly. Yet, for the most part, they complied with the direction given by the wives and/or children. Mr. Grasso "argued over terms," but usually Mrs. Grasso's interpretation of the regimen prevailed. Mr. Ambrosio sometimes objected to the restrictions his wife placed on him. He gave me the following example:

> "So we folded the laundry and put them in the position she wanted them and that was it. But she wouldn't let me take the basket up," (here, he slammed his hand on the table.) "See, to me this is wrong, I just feel that sooner or later I'm just going to do it and she won't say boo." (His voice rises in anger.)

It was over a month before Mr. Ambrosio openly would defy his wife, however. In contrast to the role exchange wives, those who valued role differentiation seemed able to convince their husbands that they were very knowledgeable of the medical regimen. What they proposed, therefore, had the ring of medical authority. I asked Mr. Grasso: "Why, for example, wouldn't you walk up the block?" He replied: "Well, I think it would be alright. My wife seems to feel that the doctor says I should stay in the house. She remembers my routine should be confined inside the house." I asked Mr. Ambrosio a similar question. His answer was as follows: "I knew she was being briefed all the time she was in that hospital. She would be getting Dr. J.'s ear (the medical director of Group Hospital) or whoever's ear she could grab." Mrs. O'Shea told me that she would not allow her husband to go to Mass although he was anxious to go. I asked her why he followed her advice now, since before the illness he often did not. She explained, "I'm known as the doctor without the shingle in this family."

Mr. Grasso and Mr. Ambrosio did increase their activities somewhat during the weeks that followed the Extension of Hospitalization. But they were not as active as their role exchange counterparts. Moreover, the kinds of activities they performed also differed from those the role exchange men were doing at this same time. Their wives were especially insistent that the men not undertake any of their former role activities. Mrs. Ambrosio tried, with considerable success, to channel her husband's activities into crafts like painting, ceramics, hooking rugs. In order that the husband not revive his interests in community affairs, Mr. O'Shea made it known to his friends that she did not want them to call him on the telephone. Mrs. Grasso would not allow her husband even to examine the records or daily receipts of their business or to help plan the purchasing for the store during this period. She and Anthony assumed these functions for him entirely. The O'Shea family was in the midst of preparing for their daughter's wedding when the heart attack struck. Because Mrs. O'Shea didn't want him "to get excited," she insisted that he not become involved with such decisions as who would be invited, or how much would be spent. She and her daughter assumed this entire function. They told me that under normal circumstances, the father would have been involved.

For a period which lasted up to two months, the wives dominated the family life. They made almost all the decisions with regard to the care, and handled all family business in this period. Compared with role exchange husbands, the men with wives who valued role differentiation were less active, and farther away from resuming normal social functions than were the others at the same point in time.

In carrying out their expanded functions, these women exhibited exceptional zeal, and were able to ward off most attempts by their husbands to resume any of their own former family activities and interests. The claim they made to full control of the nurse function was compatible with the normal role differentiated family values and lifestyle (or that which wives had been pushing for before the illness). That is, when any task is assigned, it is expected to become the responsibility of a particular family member. Others are obliged to reciprocate with appropriate behavior of their own. These reciprocal roles and obligations are ordinarily not interchangeable among the family members. When after hospitalization, the task of patient supervision fell to the wife, she did not expect to share it with her husband.

However, felt obligation to perform her duty seems not to have been the only factor sustaining the intense effort the wife made to control family life following illness. Change in the balance of influence over family affairs also brought opportunities for reward. With the wife's increased duties came secondary gains. This is related to the fact that for the wife who valued role differentiation and frequent intrafamilial companionship, the family was her major source of need fulfillment and emotional gratification. The means of achieving self actualization were contained in her life within the nuclear family. She needed others in the family to operationalize her image of a rewarding life. She had an interest in making the behavior of other family members congruent with her expectations. She could not depend on persons or groups outside the nuclear family. Being a nurse-surrogate, she could now organize the day-to-day family life so that even more than before the illness it was compatible with her own interests and aspirations. Normally, she shared control over the content of family life with her husband. Both had their own spheres of influence which made them interdependent. In some areas of their life together, there had been disagreement and disharmony. Now the wife had a chance to greatly expand her influence, and alter the patterns she found particularly disagreeable.

The wives who had the most to gain by controlling the recovery were the two from role-dissensus families - Mrs. Ambrosio and Mrs. O'Shea. Their pre-illness disappointments over the content of home life had been great. In contrast to their present positions, before the illness they had little success at influencing their husband's behavior.

An indication of how successful the wives who valued role differentiation were in establishing the legitimacy of their claim to home care control was that when husbands did deviate from wives instructions they did so <u>in secret</u>. When the couple was together, the husband-patient sometimes complained but almost never went directly against his wife's wishes. The wives were prepared to act forcefully to meet any deviation from their policies, and the men reported that they were aware of the conflict that could follow when they did not follow orders. This is illustrated by the following:

I said to Mr Ambrosio: "I saw that big branch was gone." He replied: "I have a Swedish saw. No sweat, only I had to do it when she wasn't around." I said: "I guess she noticed."

He answered: "No, and I haven't said a word either. (I did it) Little by little....it could have led to a divorce."

Anthony Grasso reported that after his mother discovered Mr. Grasso smoking a cigarette, she yelled at him: "She yelled at him and he took it with his head down - like a little boy."

Along with the similarities I have described, the emotional climate during this second stage of home care was not the same for the role dissensus families as it was for the Grasso's (consensus on role differentiation) where prior to the illness both spouses actively supported a role differentiated family structure. Mr. Grasso perceived his identity as a man threatened by his patienthood. With his wife and son substituting for his normal family functions he felt it was a loss of self-esteem. This period of convalescence was for him a degrading experience and his morale suffered a severe blow. As a consequence, interpersonal relationships in the family became strained.

V. The Honeymoon Period in Role Dissensus Families - Reorganization in the Ambrosio and O'Shea Families

The restrictions the regimen placed on the men and which their spouses reinforce brought immediate gains to the wives. Mrs. Ambrosio explained it this way: "I always felt my husband did many things that I could do that he wouldn't let me do, and I feel so stupid in so many things. I feel that now he should let me." She took over as many household chores as she could manage to do: food shopping everyday, even though there are only two of them, preparing all the meals and then doing the dishes, shopping for her husband's clothing and selecting what he would wear during the day - all things which she wanted to do before but could not because her husband did them first. She was finally in control of the household. Whenever I saw or spoke to her during the weeks of the second stage, she appeared happy and spoke enthusiastically of her daily routine: "I never felt better in my life. (My younger sister) is always saying on the phone; 'Are you resting? Are you resting?' But when she came she said: 'My God, you look wonderful.'" The chores she was so happy doing were "wifely" chores, ones which prior to the illness she wanted to be in charge of. "It's a nice feeling getting up early, it's dark, and I get the breakfast ready, put the shades up to let the light in. Then I wait on him." (My emphasis) Mr. Ambrosio was both surprised and impressed with his wife's energy. He told me: "Like this morning, she said she got up at 4 A.M. I said, 'What the hell did you get up at four?' She said: 'I want the floor washed. I really want to know why you get up so early, what is the advantage. I'm suddenly finding out: it is peaceful, quiet, there is no interruption, telephone or other duties.'"

Mrs. O'Shea reported the same type of rewarding experience during this part of the home care. She was able to actualize her wishes for an orderly home, in which activities followed a definite routine:

> We eat on time now. My life doesn't revolve around the Knights of Columbus, or anybody. It revolves around me... I hated that. I wanted to eat at a certain time, I'd get a phone call (from her husband) 'I'll be a half hour late, and a half hour would go into an hour... I got like a hound dog... I have the say now. I don't get, 'Well this is my job...if you don't want to wait, don't wait...' Everything is Me, what I have to say, no more what he has to say... Now (he says) do <u>you</u> think, not: 'I'm going to do it this way.'

Both women utilized the inability of their husbands to participate outside of the home to increase their own closeness - to substitute themselves for their husband's separate friends and interests. This was something these women had wanted to accomplish prior to the illness but could not. Companionship with the husband was a major desire for role differentiated wives. Before, Mrs. Ambrosio and Mrs. O'Shea were denied it, but now the situation enabled them to have it. Mrs. O'Shea related: "I was always around. Now I have a companion. It is better for me... It is for my benefit for a change. He checks the programs for us to watch... We talk back and forth. Normally, I would be staring at the television with no one to talk to." Mrs. Ambrosio, who had a very active life outside the family prior to the illness, ceased all of these involvements and was glad of it. She told me that she only got involved because she had no family role before. She claimed that what she was doing now at home pleased her more than church and community activities. She liked reading to her sick husband, talking with him, helping him with his hobbies, and most of all providing nurturance and service.

Mrs. O'Shea's advice to her husband seemed designed to separate him from those external forces which she blamed for his very active life apart from the family. She blamed his friends, "bad guys" she called them, for his past neglect of her wishes and now during the convalescence she used her influence to make his medical condition appear incompatible with his formed friends and activities. She discouraged his friends from visiting him. She told me: "I have not let anybody come up here. He will want to be the host...If friends do come I'm not afraid to say, 'Tom has to go to bed now; or 'I can't allow smoking around Tom now.'" Yet, at the same time, she portrayed them to her husband as unfaithful friends for not visiting: "People he was very friendly with have never called. I say, I told you so, I never liked that person. Then I'm in my glory: 'Don't give me any of your bad guy friends.'"

When Mr. O'Shea began to feel well enough to go out for brief walks, Mrs. O'Shea sometimes used who he was likely to meet as her criteria for approving or discouraging the activity. For example, her argument against his going to Mass was: "You know everybody is going to talk to you. It isn't that you are going to go and come back, everybody will grab you in the back of the church." On the other hand, during this same period, she encouraged him to go to a wedding of her relatives, even though he was not inclined to go, fearing adverse physical consequences. In this case, she argued that "talking to people will do him good." In other words, she encouraged him in activities which they would do together, and discouraged him from those which involved his friends. She substituted for his friends.

Without his friends and his church activities, Mr. O'Shea began to look forward to his wife's company. When his wife came home from work at 3:00 P.M., he was openly glad to see her and, in a switch of patterns, got angry if his wife went out in the evening to visit her friends. As the rehabilitation progressed, closeness between Mr. and Mrs. O'Shea increased. They developed a new ritual. In the afternoon, as soon as he saw her step off the bus (he looked out the window around the time she should be arriving), he would start brewing a pot of tea and make her a snack. Then they would eat and talk. If he failed to prepare this snack, Mrs. O'Shea would express disappointment to him about it. She came to expect it. He started driving at his wife's urging - she needed to be driven home from her daughter's shower. This was prior to the doctor giving approval for this activity. For several weeks thereafter he picked her up from work in the afternoon and then drove her shopping. Formerly, she did these chores alone.

One of the reasons why Mr. Ambrosio was pleased to have his wife close by was that he perceived her as having a positive effect on his progress toward health. Mr. Ambrosio admitted that even though there were times he wanted to disagree with his wife and do more than she allowed, "She is right in many respects." He seemed pleasantly surprised at how much she could accomplish around the house, and how adroitly she managed his care. His wife reflected on his sentiments during the first month of the home care: "I think he has a little more confidence in what I'm doing...He told me he owes his life to me. In letters he writes, people tell me: I give him tender loving care. If it wasn't for me he wouldn't have made it."

Under her supervision, Mr. Ambrosio felt confident that his health was improving. He said: "I've learned what foods to eat...I can feel an infusion of energy into my body. Because now for the first time I'm eating like I should be eating... I would have pancakes piled up to here. Marie would not follow through. Now, if I do she is right on me with a baseball bat."

Neither Mr. O'Shea or Mr. Ambrosio gave indications that their present passive role challenged the security of their self images. In the normal course of their day-to-day lives prior to the illness, neither person was concerned about sex role boundaries. Both were willing - even anxious - to do activities traditionally ascribed to females in our society. Having their wives temporarily substituting for them was not intrinsically threatening to them. Mr. Ambrosio reflected on the role that his wife was currently playing, and seemed willing to accept the change in their relationship, at least for the present.

> She said like a school teacher: 'Don't you worry about a thing, you just do as you are told'...(E.S.: Is that something characteristic of her to give you an admonition like that?) No, there it points out - I think this is characteristic of all women - the motherly instinct comes out. Not the wifely instinct, per se. First the motherly instinct: 'You are the little person, you are sick and I have to treat you like an invalid... and you are going to listen to me.' OK (he said to her), if it will make you happy I will do as you say.

With Mr. O'Shea not working, the financial burden of the family was the sole responsibility of Mrs. O'Shea. While the decrease in income troubled Mr. O'Shea, the fact that he was not the family breadwinner was not in itself a problem to him. He hoped that the promotion and raise his wife was scheduled for would make him less worried about the family's finances. It pleased him very much when his married son offered to give him a sum of money whenever he needed it.

Comparing life in the Ambrosio family during the second stage of home care with what it had been like before the illness, one cannot fail to notice the remarkable improvement in the wife's morale and self image. Moreover, the marital relationship itself was noticeably more harmonious. There was little of the former arguing between the spouses over who should take responsibility for household tasks. Mr. Ambrosio, for the most part, appeared content to play a passive patient role, which he perceived as necessary for full recovery later on. Occasionally, he verbalized impatience, and even acted against his wife's wishes by going to the mailbox in the rain or walking farther than she wanted. But when his wife corrected him, he resumed a compliant posture without becoming hostile. His wife seemed to thrive on nurturing him. She liked reading poetry to him, selecting what clothing he should wear, and what and when he should eat.

It is difficult to exaggerate Mrs. Ambrosio's happiness over her role. Doing everyday mundane chores seemed to delight her. After she salted down the sidewalk after a frost, she remarked to her husband and me that she felt like a young girl on her parents' farm feeding the chickens. With a sense of self discovery she discussed a book she had just read about the positive aspects of being middle aged. "It is truly wonderful," she exclaimed.

In accepting his wife's control, Mr. Ambrosio seemed content. Yet there were some signs that the future would not be as harmonious as the present was. Mr. Ambrosio perceived the present state of affairs as temporary. I asked him if he though he would ever again resume all of his former activities, many of which his wife was now taking delight in. "Oh yeah, I want it that way. This is my job... This I expect to do. I know damn well that she will literally have to hold me down...these things I want to do myself; take the car out, take the garbage, go shopping, make contacts, go back to my consulting work..." This was not the impression Mrs. Ambrosio conveyed, however. While she did not expect to continue to do quite as much as she was now, she perceived the illness as having brought a permanent change in the marital relationship. Her understanding of the consequences of the heart attack was that the husband would never be able to go back to a highly active lifestyle. She recalled that one of his doctors had told her he would never be able to do anything as strenuous as changing a tire on his car. The couple, however, never seemed to discuss future adjustments. They concentrated their interaction on the present. Interestingly, the couple's married daughter and son-in-law also assumed that the changes which occurred since the illness would be permanent ones. They spoke as if Mr. Ambrosio had experienced a fundamental personality change.

When one considers the pre-illness relationship in this marriage, the failure of the couple to exchange expectations about the future role allocations during the second stage of home care fits a pattern. Control of family functions had always been a struggle between the spouses. Each had perceived the other as a potential barrier to self-fulfillment of role expectations. Now, Mrs. Ambrosio was counting on the illness induced limitations to preclude many of her husband's past activities. But Mr. Ambrosio was confident that soon the need for the wife's services would pass, and he would be able, as he always had been, to assume the bulk of household functions.

VI. The Burden and the Promise of Role Adjustment - The Grasso's

The experience of the Grasso family demonstrates that the second stage of home care can be a troubled time for a family, in spite of the increase in control by the wife.

Mr. Grasso was very disturbed by the restrictions on his activities. While he complied with his wife and son's directions, he resented being subject to their authority. He argued, complained and criticized the present state of affairs. Mrs. Grasso, however, was unrelenting in her insistence on making all the decisions regarding her husband's activity. Prior to the illness, she tried to influence his behavior in a quiet way, in conformity with her feminine image. Now, however, she openly pushed her own position, and argued in "an unladylike way." She told me: "I nag him all the time: What did you eat? Are you allowed? Did you go down the stairs? He gets annoyed, but that's how I play my role."

Having his wife and son plan and operate the family business, and do his household chores repulsed Mr. Grasso. He felt deeply about his masculine breadwinner role and seemed unable to adjust to a passive patient role which he told me was humiliating. He said to me one day: "It used to be that she waited by the window for me to come home. Now, I'm waiting for her to come home. It is not easy... I'm not being chauvinistic, but it is not easy for a man to do."

Anthony also felt somewhat ambivalent about the role he felt obliged to play in the home now.[19] Criticizing his father's behavior seemed out of character even though he felt it was needed now. His father gave an illustration of the conflicting roles of son and nurse-surrogate: "I lit a cigarette the other day. I shouldn't and he caught me smoking. He chewed me out as much as a son would dare to chew a father out. He was embarrassed. (E.S.: Why was he embarrassed?) The fact that he caught me doing something wrong. He walked out of the room, mad, but he didn't say anything angry to me. I felt so bad; I threw the cigarette away immediately." The requirements of illness had altered the basic structure of parent-child relations. Father and son both disliked it. Anthony and his father had always formed a coalition in which they attempted to influence the direction of certain family matters which Mrs. Grasso was opposed. The strong bond between father and son was something each family member reported to me. Anthony seemed especially gratified by it. However, his present role in the rehabilitation was stressful to him because it resulted in a coalition between mother and son vis a vis father. Yet, Anthony felt that this was what the situation required. An example of the son's aggressiveness in reinforcing the regimen is the statement he made to his father: "If I ever see you smoking a cigarette, I'm going to punch you in the mouth."

Mr. Grasso, in describing his first trip to the doctor since homecoming, illustrated his new isolated position in the family: "Anthony came with me, not so much for company, but I think for - they play games with me. They want to be sure I don't lie to them, if when I ask the doctor if I can go to the store (business) I would say yes, when in fact he had said no. My wife feels that I abuse the doctor's warnings. I'm pretty sure that's the only reason Anthony was there."

Unlike many of the other men at this time, Mr. Grasso had serious doubts about ever getting well - even if he conformed to a very conservative regimen. He stated:

> "But somehow I feel that sometime I'll go back there again, not with a terminal attack, but I'll have reason to go back to the hospital with some kind of heart attack again... one of the doctors said it... my wife thought that was very silly but I don't think it was silly. I feel that way...whatever conditions put me there the first time still prevail and it is not a matter of eating too much chocolates or smoking too many cigars either. It's just a condition that is within my constitution that just does not leave by cutting out sugar and smoking."

At home he did stop smoking (for a short time at least) and for the first three weeks generally followed Mrs. Grasso's advice, although with reluctance. He said in our first talk at home, "I feel very well, very good, just restless. I feel strong enough. I have no worry about being able to walk a block or two. I'm afraid because the doctors didn't say that I could. I'm trying to do the right thing. Whether or not I think it is right or wrong I guess doesn't matter." Moments later, he indicated that he felt a responsibility to cooperate with his family who he saw as suffering because of his illness. "I say the problem, whatever put me there, will never be cured... I can't change that by eating different. I'm trying to be calm. I'm going to try to change. <u>I promised. I owe it to them to change</u>." (My emphasis)

Without his felt obligation to subordinate his own preferences to the demands of the group, which is required under role differentiation-high companionship values, Mr. Grasso's rejection of the institutional definitions and prescribed procedures to cure, control or minimize the effects of the illness would probably have led to a "retreatist" behavioral response. Merton defines the retreatist mode of adaptation as follows:

> Retreatism seems to occur in response to acute anomie, involving an abrupt break in the familiar and accepted normative framework and in established social relations, particularly when it appears to individuals subjected to it that the condition will continue indefinitely... it often obtains in those patterned situations which 'exempt' individuals from a wide array of role obligations, as, for example, in the case of 'retirement' from the job imposed upon people without their consent...[20]

Yet, Mr. Grasso made an effort to conform to a set of expected behaviors even though he failed to see the usefulness of them, and experienced psychological stress in carrying them out. The evidence is that the weight of the family's collectivity orientation created a sense of obligation on the part of the patient to conform with the expectations of the group. However, the discontinuity between his subjective feelings and the demands of social obligation made conformity difficult, and there were lapses in it. His inner tension was expressed in aggressiveness, anger toward his wife and son, and depression - all of which contributed to the overall family climate during the second stage of home care.

In playing her role, Mrs. Grasso had to deal with these tensions. Anger on her husband's part did not diminish the extent of her attention to the details - large and small - of his care. She determined whether the doctor's order to rest at home meant that the husband could not sit on the porch in the sun for a few moments. She determined when he was able to see his friends, and to join in the card games. To her husband's chagrin she even answered for him when friends inquired about his treatment regimen.

According to Mr. Grasso, his wife derived a measure of satisfaction over her success in controlling his behavior. With friends, she discussed her role, and he listened in: "You overhear: 'Is he resting"' 'Yes, I won't let him do anything. He wants to go outside. He wants to work. I won't let him,' my wife would say proudly. She refused to let me outside, and its a feather in her cap."

Mrs. Grasso paid a personal price for her nurse role. She reported that overseeing her husband's care left her little time for much else. She was up late doing housework. When she came home from work she had to do the bookkeeping for the store and the planning for the next day. She was forced to eliminate such activities as going to the beauty parlor and watching television. She claimed she hardly had time to prepare her clothing for work. The fact that her scrupulous attention to her husband's behavior was not conducive to warm interpersonal exchanges with him was also troubling her. Nevertheless, she showed no inclination to reduce her involvement in the care. When laboratory results showed that Mr. Grasso's condition was improving, the wife felt justified in her actions, and strengthened in her will to continue as home care supervisor.

The adjustments made in the Grasso home following hospitalization interfered with the normally close emotional ties the family enjoyed. Mr. Grasso was "left out" of normal family affairs to a very considerable degree. There was an awkwardness to interpersonal relations. Home care roles were in the familiar role-differentiated style but they did not now facilitate companionship and communication. Mrs. Grasso had control, but Mr. Grasso was isolated.

The following example of a not untypical evening in the home during the second stage of the home care illustrates the strain from the role adjustment. Following illness onset, Mrs. Grasso and Anthony assumed full control of the family business. It was the wife's decision that her husband was "too sick" to do any planning or bookkeeping, although he wanted to and felt able to. (The following episode was constructed from my conversations with each family member):

> After dinner the books and papers relating to the store's operation were brought to the dining room and Anthony and Mrs. Grasso began discussing the day's receipts, and planning for the upcoming Thanksgiving holiday. Decisions had to be made about how much new stock to order, how to display it, and whether or not to open early during the week of the holiday. Mr. Grasso was sitting in the living room about twenty feet

> away and was turned toward the television. He could see and hear his wife and son through the wide passageway separating the two rooms. Mr. Grasso said nothing, but later each person would report being highly conscious of his exclusion. Outwardly, all was calm. But this belied the tension each felt. While Mr. Grasso seemed to ignore events in the next room, he was tuned in. When the others went to bed, Mr. Grasso returned quietly to the dining room and examined the books and order forms. He was unaware that his son was watching him.

VII. The Family Perception of the Medical Care System

As we have seen, a common problem which confronted role exchange, role differentiated, and role dissensus families alike was uncertainty about the husband-patients' fitness to undertake activity at home. While husbands and wives were sometimes in disagreement over the extent to which activity posed a danger to health, all the spouses and children lived with an acute sense of doubt and fearful anticipation of potential illness reoccurrance. Yet, no one attempted to contact the family physician, either for reassurance when the newly homebound heart patient experienced symptoms of various kinds, including chest pain, or to try for an earlier appointment. Moreover, when people did see the family physician they did not generally seek his help in resolving the differences in interpretation of the regimen over which spouses often found themselves in conflict.

While this behavior may indicate that family members were attempting to avoid facing up to their problems and so denied them, the fact that they were willing to express to this researcher not only their fears and conflicts, but also their need for medical system support, suggests alternative hypotheses. On the basis of remarks made to me by patients and other family members both prior to and after hospital discharge, there is evidence to claim that there was widespread misunderstanding of the role that the medical care system would play during the home-based recovery period, and much confusion over the role the family physician was to play. This seems to have contributed to confusion about the kind of services they could expect to receive from Medical Group, when they would receive them, and ultimately to a decline in confidence in the medical care system's professional expertise. Lack of sufficient knowledge of the role of the family physician, and of the system for continuity of inpatient and ambulatory services, rather than denial of problems, prevented the families from making more of a claim to the expertise and support of Medical Group. In view of the observations made at the start of the illness when delay in getting to Group Hospital resulted, in several instances, from lack of understanding of the procedures for utilizing emergency services, the finding of Roemer's[21] study group seems to apply to Medical Group. Roemer, et al., made the observation that organizational complexity of group practices can be a barrier to client utilization of services because people are unused to dealing with bureaucracies for their medical care.

As was mentioned in Chapter One, Medical Group's arrangement for coordinating in-patient and ambulatory patient care services was different from that provided by the traditional mode of health delivery under which health consumers pay a fee to a private practitioner for each service rendered. When clients of Medical Group enter Group Hospital, their family physicians do not provide direct patient care, as often occurs under the traditional form of medical care delivery in this country. Rather, physicians on assignment to Group Hospital plan and carry out necessary diagnostic tests and therapeutic procedures. If the family physician so chooses, he can visit the patient in the hospital but cannot assume responsibility for the care. For example, the family physician cannot order laboratory tests, or write orders for medication. The family physician does, however, resume patient care responsibilities once patients are discharged from the hospital. This procedure is followed regardless of the reason for admission to Group Hospital.

We saw, however, that patients and family members attributed the absence of the family physician from the in-hospital phase of the care to limitations in his skill and knowledge. The family physician was perceived as less than adequate, by virtue of his training, to care for victims of heart attacks. In contrast, the physicians who provided care in the hospital were perceived as specially trained experts in heart disease. Patients and family members, therefore, expected to receive continuing medical care services after hospital discharge from other specialists, if not the same ones they had in the hospital. A short time after Mr. Grasso had been home from the hospital, he reflected on the kind of continuing medical care his condition required. He said, "If I could have an examination by a good heart man, a good cardiologist, a good x-ray man, good blood people, good dietician... I'm sure it would head off any coming heart attack."

Several people mentioned at home that they wanted more than a periodic examination by a cardiologist; they wanted such specialists to be in full control of their care. Mr. O'Shea responded to my question about when he was going to make an appointment with his family doctor this way:

> Yes, my wife was down there and he (the family doctor) said he wanted to see me. She was a little confused about what went on. She told him I was supposed to see the doctor I had in the hospital. Which isn't so... I'd like to get transferred to that doctor who is connected with Group Hospital. I think he's the resident in Internal Medicine... I imagine he is involved in the heart. So I think I'd be much better off if I could transfer to him... I guess the Internal Medicine group handles it after a heart attack, don't they? I'm not anxious to see that family doctor. I'd really like to see that (cardiologist). (E.S.: What would you like to happen at that meeting with the cardiologist?) To find out how I'm coming along. If I can go back to this job I have.

Clients of Medical Group have the right to consultation by a specialist. The unusual procedure is for the client's family physician to arrange for this when the person asks. However, Mr. and Mrs. Ambrosio expected that the specialist the family physician arranged for him to see would provide continuous care. His wife related that after they learned that this would not occur, and that the family physician was still the main source of care, they were both disappointed. She told me:

> On the way home I said 'When does he want to see you again?' He said, 'Oh, he won't have to see me anymore, just go back to (the family physician). I said, 'I think it could be a good idea if Dr.Jones (the specialist) saw you all the time.' He snapped at me and said, 'Shut up'... We were waiting so long to see Dr. Jones and expected to be under his care... I was disappointed that Dr. Jones didn't do more and then follow up. I felt he would be the internist's patient.

I asked if she also thought her husband was disappointed. She indicated yes, this was the reason for his hostile reaction to her on the way home, but added "he figured that what Dr. Jones said was the law."

One of the claims made for the group practice mode of health delivery is that patient care can be made more rational and more efficient through the integration of research with service goals. Members of a larger group practice provide a defined population for basic sciences, epidemiologic, and social science research. Ideally, the finding of scientific studies contribute to effective coordination of medical care services.

At the time the eight men in my study were patients, Medical Group was involved in a study to learn the long term physiological effects of myocardial infarction. Either just before or after they were discharged from Group Hospital, each of the men was asked to participate in this project. All but one patient and spouse failed to distinguish this research project from medical care. In other words, most people believed that this was Medical Group's procedure for providing them with the expert care they believed they needed. Since they were told they would be contacted for testing within a short period, some people may have felt that there was no need to request a specialist consultation from the family physician. It appears that patients benefited from participating in this research activity of Medical Group because test results were supposed to be passed on to the family physician. However, a potential disadvantage for the system and the patient was that in misunderstanding the purpose of the research project, patients may have failed to utilize medical care services which they felt they needed, and to which they were entitled. For example, had they known that the testing to which they were invited was primarily for research purposes, more patients may have asked to be seen by specialists, and they may have requested this soon after hospital discharge. Several persons I spoke with after their testing said that it was less helpful to them than they had expected because "it's only research."

Had patients and family members known earlier that the major responsibility for their care rested with the family physician, they might have utilized him more effectively. Believing that a physician more expert in matters directly pertaining to their needs would soon be involved in their care, people may have had reservations in accepting the advice of the family doctor, and postponed asking many questions. They may have preferred to wait for the chance to talk with "the expert." Based on what patients and their spouses told me of what transpired during their visits to the family physician, they asked few questions of the doctors and reported having as many doubts about their condition and what to do about it after the meeting with the family physician as they had before they went.

On the other hand, it is possible to argue that by the time the patient was discharged from the hospital his expectation that he needed a higher degree of expert help than his family physician could provide was already firmly established. By that time he may already have determined that he neither needed nor wanted the assistance of the family physician for this health problem. In a very real sense the organization of Medical Group's health care delivery system may have created needs and expectations among the patients and their spouses which the system never intended, and therefore, could not subsequently meet.

At the start of home care, each family faced hard problems. The most worrisome arose from lack of confidence that the home environment could protect the recovering heart attack victim from relapse. Without the direct supervision of medical experts, wives, children, and patient-husbands were afraid to make independent judgements to interpret the medical care regimen. Instead they took what was felt to be the safest course, i.e., having the patient adopt a routine modeled on the Intensive Care Unit. As difficult as this period - The Extension of Hospitalization - was, the source of family problems were seen by the members to be from the outside. The illness was conceived as an external threat and the members joined forces to protect themselves from its effects. Consequently, interpersonal family relationships were generally harmonious. Working together seemed to bring a measure of well-being to families under the threat of crisis.

The nature of the problems families faced changed in a qualitative way, however, once the patient-husbands decided to become more active. Since their decisions were based on definitions of the recovery process which were not shared by their spouses, the tendency was for wives to oppose the actions of the husbands. Now family members could blame each other for thwarting the chances for recovery. Family problems centered on conflict between members.

As we saw in Chapters Two and Three, discrepencies in families in understanding the nature of the threat of illness and the requirements of the recovery process originated during hospitalization. The consequences of this lack of consensus, however, only surfaced a week or two after hospital discharge.

Because there were no organized mechanisms at Group Hospital to allow definitions of the situation to emerge, the families were not able to work through their differences at a time when professional social service or psychiatric personnel could have helped. Instead family members had to cope alone in a situation already tense and worrisome. The fact that lack of coordination in the hospital between patient and family experiences produced problems when the patient arrived home had no way of being fed back to the hospital staff for system correction. Since a large part of the social and psychiatric services available to patients and their families are allocated on the basis of referrals made by hospital medical and nursing staff, one can see how many families which could profit from professional counseling go undetected and unserved.

We saw from the analysis made in this chapter, that strategies for managing the home care reflected the organization of the family. Whether the family's structure and value climate would have played such an important role in organizing the home care had the medical care system played a more active role is hard to assess.

Couples in role-exchange, low companionship families were the first to disengage from acute care roles which were adopted at the start of homecoming. As a result, patients in these families began the process of resuming pre-illness roles earlier than their counterparts in the other two types of families. Their early mobilization was aided by the general feeling of discomfort in their families with the type of interaction fostered by a patient-nurse surrogate relationship. Segregating members into highly reciprocal interdependent roles was antithetical with the arrangements which were valued and practiced prior to the onset of the illness. With an aim toward avoiding conflict which had surfaced when wives tried to play controlling nurse-surrogate roles to husbands' passive patient roles, the couples opted for a home care division of labor which allowed each partner to participate. Their strategy for dealing with home care management was basically a way of balancing the requirement of the recovery with the demands of family norms and mores.

In families where there was a value placed on role differentiation and intrafamilial companionship, couples remained in patient and nurse-surrogate roles for a longer period than the role exchange couples, and the men had fewer opportunities to test their abilities to resume activity. We saw that for couples which had been in conflict prior to the illness over role expectations and performances, the home care brought a significant degree of harmony to marital relationships. There was secondary gain from the illness in these families. In the following chapter we will show how normalization is affected by the fact that for some people illness is rewarding psychosocially.

Given a context for rehabilitation in which family structure and culture influences how people behave after hospital discharge, it is significant that the medical care system left rehabilitation decision making so exclusively in the realm of the family of the patient. It was not until approximately three weeks after the start of home care that the patient had his first physician visit. By that time certain patterns had already emerged with respect to how he perceived and behaved toward his medical problem.

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Chapter VI

Normalization: The Costs of Reentering Normal Social Roles

Several authors[1-3] have taken up the theme first suggested by Reuben Hill that the family's response to crisis is like a ride on a roller-coaster. What seems to be a typical experience is that no sooner has a family managed to cope with one set of problems when it is suddenly beset with new, unanticipated difficulties. As has been pointed out by Strauss[4], chronic illness can be particularly hard for the ill person and his family to manage because of the uncertainties in anticipating the pace of recovery, discrepancies between peoples'definitions of what is expected of the disease, and sudden shifts in the ill person's condition. Strauss explains that at each step in the patient's career, "...the ill person must reassess where he is and therefore what social arrangements are necessary in order to manage his symptoms, social relations, daily life, and preparations for his life in the foreseeable future... In a genuine sense, any chronically ill person who phases drastically down, _or up for that matter_, becomes a new person in the house."(my emphasis)[5]

For the recovering heart patient and his family, it appears that the step toward normalizing one's social life can be the time of greatest strain.

By the third month of the home care, five of the men (Polski, Asti, Stein, Ambrosio and Grasso) appeared to resume premorbid activities in a sudden rush, as though there were a sense of urgency about the need to become more active. In explaining the reasons for undertaking arduous activities which they had not done since entering the hospital, the men spoke of "pressing need" in the household, or in their personal lives which "just cannot wait any longer."

Mr. Polski used his son's impending return from military service as the reason for increasing his efforts to finish constructing his country home. He claimed that because he had promised to give his son this house, he had to have it ready for him and could not stop work, even if pain or fatigue increased as a consequence. Mr. Asti focused on an upcoming trip to Florida as he took on the heaviest activities since his heart attack. He told me:

> See, one of the things I did do in the last couple of weeks I was doubtful about doing. I was afraid to do it, but I went ahead anyway. I changed the plugs in the car...tuned the car up. I was doubtful whether I should do it or not, but I went ahead and did it anyhow...I was concerned about doing it. I felt maybe I was doing the wrong thing...even though the doctor had said he didn't want me to drive to Florida. My wife would drive, my brother-in-law would drive. Iwanted to make sure nothing went wrong with the car...As it turned out, we decided to fly down. If I had known that I wouldn't have done it.

Mr. Ambrosio began to openly ignore his wife's admonitions to caution at the time two court cases in which he was to testify as an expert witness and which had been postponed due to his illness, were placed back on the court calendar.

While these "important tasks" had significant meaning to the patients, they did not appear to this observer to warrant the urgency that the men displayed. For example, Mr. Asti could have had a professional mechanic tune up his car. Mr. Ambrosio admitted that the cases could be postponed again, or substitute witnesses could be called in his place. The function of the "important event" was to give impetus to men who very much wanted to return to normal social functioning but who were highly uncertain of the costs of such a move. The sick role had become intolerable, yet the men were still unconvinced that they had the ability to stand up to the rigors of normal social activities. They were untested for what they wanted to do. The important event pushed them - against their will as it were.

From the interviews with the men at this time, it may be postulated that an important factor in the decision to move substantially away from the sick role is a sense of fear that continuing to be relatively inactive might lead to permanent disability. Mr. Polski expressed a common theme among the men:

> Maybe I'm harming myself by not sitting down in a rocking chair like they want me to. I'll be 65 next week(long pause). If I sit down I'm not going to get any younger, and if I sit down for a month I'm going to be that much older, and I won't want to get up anymore and do these things. While I still have the urge and ambition to do it, I want to do these things.

Making full use of the time before age would itself limit their strength and reduce their activities seemed an issue which concerned the men. One said: "As you get older there are so many things to get done and you have such limited time to do it." Mr. Grasso, who was in his fifties, was also very upset about the possible effects of what Singer[6] has called "premature social aging". Mr. Grasso said that if he were an older man he might be able to continue the relatively inactive life his wife was urging him to follow. But at this stage in his life, he felt an acute need to return to full activities:

> I cannot say, 'OK, I'll sit in the easy chair and you take care of me'. It might make her very happy if I say I'mnot going to go to work anymore, I'm going to put on my slippers, I won't smoke anymore, I'll put on an old sweater and watch TV. I won't lift a thing the rest of my life. She might be happy. But I'll be miserable. And I'm selfish at least that much, to say I don't want to be that kind of miserable to make people happy... So I've got to contribute something, so I'm going to go out and do some work.

These five "full activity" patients wanted to get well, which, as Parsons[7] tells us, is expected of the sick in a society which values achievement, activism, and worldliness. They rejected the illness, accepted the obligation to get well, and wanted to cooperate in an active process toward that end. However, they came to perceive the regimen as oriented toward keeping them in a state of disability, and they were troubled by the fact that the regimen did not appear to be providing them with the means whereby they could take an active role in working toward their recovery. They felt they were being denied access to the means and they were forced to find ways of innovating to achieve their goals.

The patients wanted the doctors to be active, to do <u>something</u> and to prescribe something which they, the patients, could do as well. Mr. Polski wanted his physician to perform surgery to open his clogged arteries, and after he was told that this could not be done, he said to me that he would extend the time between visits to the doctor. His main purpose in going to the doctor became acquiring refills of his nitroglycerine - which was a means of allowing him to do his normal round of activities. Without this medication, Mr. Polski would have been prevented by pain from doing the heavy construction work he began to do. Another patient, Mr. Ambrosio, said, "I'm tired of hearing, 'Don't do this, don't do that', I want to know what I <u>can</u> do."

At this stage of the recovery process, the men tried to elicit from their doctors approval to return to normal activities. Mr. Grasso asked for permission to return to full time work; Mr. Ambrsio asked to be able to travel to Florida to visit his sick mother, and to return to his consulting work; Mr. Polski wanted "pep pills" to enable him to work harder around the home. They told me that the response of the physicians was to continue "taking it easy", to increase their activities gradually, and not to work when they were tired or felt pain. While none of the men actually resumed premorbid activities completely, they all appeared willing to selectively deviate from some part of what they understood to constitute doctor's orders. When I asked Mr. Polski, Ambrosio, Stein, and Grasso if they felt they were in full compliance with the advice of their physicians, each replied that in some of their present activities they were not. Mr. Asti's response to this question was always, "I don't really know."

Two of the men, Mr. Ambosio and Mr. Grasso, expressed a redefinition of their illness - one which would justify an expanded routine. They told me they had come to a determination that their major health problem was really diabetes, not heart disease, and because of this, activity was needed to "burn up the sugar." Mr. Ambrosio explained his position this way:

> The doctor said...'When you start to get tired, when you get a shortage of breath, stop.' I said, 'Can I tell you something? Since the day I came out of the hospital...I have not had any pains or aches. I get no shortness of breath'. And, of course, as I said many times (butnot to me or his wife until this point) I still believe that it was the diabetes and not my heart per se...I don't have these symptoms, I know there was something wrong, but to what degree? It might have been minimal compared with what these other fellows had (who were in the hospital with him) (ES: Did you mention this opinion of yours to either doctor?) Well, I talked to them, but you know, they look at you with a cork screw eye: Who the hell are you to tell us...So they sort of discounted it. He said, 'No, you had a definite coronary.' They always associate the diabetes as secondary to the coronary. In my opinion, it is the diabetes and then the coronary

Mr. Grasso also argued that the pain problem now was diabetes: "I worry more about the diabetes, because I can't control the heart, but I can control the sugar. Whatever has gotten to the heart has gotten to it, I can't do anything about it."

These changes in attitude and in behavior were followed by the re-emergence of conflict in the families involved. Both the role differentiated wives, who had been controlling the rehabilitation up to this point, and the role exchange wives, who had tried to have influence by persuasion, responded with a combination of fear and anger.

The intensity of the ensuing struggle was greater by far then it had been previously. No period in the illness crisis was as conflict ridden for the families than the one which followed the onset of husband-patients' normalization activities. No period brought as much emotional hurt to the members or so disturbed family solidarity. In the beginning of the crisis, when life itself seemed to be threatened, the members had each other for support, and, in most cases, reported that interpersonal relationships within the home were better then they were before the illness. The family had then closed ranks against the disaster.

It was generally agreed that the conflict over normalization was equal to, and in some cases, surpassed what the family had experienced in its history. As a consequence of the hostilities, two wives threatened to separate from their husbands. Moreover, three wives reported their own health was adversely affected. Mrs. Ambrosio had her first attack of osteoarthritis since before the heart attack; Mrs. Stein,who herself suffered from angina pectoris, had to increase her dosage of nitroglycerine; Mrs. Polski went to the doctor complaining of unexplained weight loss and dizzy spells. Before the issues were resolved, Mrs. Stein would die of a heart attack, and Mrs. Ambrosio would be instititionalized for a nervous breakdown.

On the other hand, life in the O'Shea, Goldberg and Warren families, where the men continued to behave very cautiously and inactively - like sick persons - was not troubled by conflict. In each of these three cases, the men accepted that for the foreseeable future, they would be disabled, and would refrain from resuming significant portions of their pre-illness lives. Accepting disability seemed to shield against family conflict and personal anxiety. Returning to normal functioning for the other five heart patients meant facing a period of inter and intrapersonal conflict.

In addition to family fighting over what the regimen allowed and did not allow the men to do, the tension the men felt because of their own uncertainty over their activities contributed to the climate of unhappiness. Mr. Asti found one "important task" to do after another. Each he approached warily, even at times fearfully, but with determination. For example, I asked him, "You said you felt tired, does that mean you had pain?" Mr. Asti replied, "No, but I was under tension. I didn't know if it was going to be harmful or not. It wasn't much as far as physical exertion is concerned...I was just worried about the after effects, would they cause me pain or harmful affects afterward?" The tension that he experienced seemed to be directly related to the changes which occurred in his behavior toward others in the home. Rose, his daughter, summed up his behavior as "nasty". He became uncharacteristically critical of others, and then seemed to withdraw by not talking to anyone. This behavior caused his wife to become angry at him and there was bitterness and loud shouting in the home. Activities he was engaging in at this time were substantial ones: cementing the patio, shoveling snow. He claimed that he had to do these things when his wife objected or else "the whole patio will get ruined; or "someone will slip".

Rose herself vascillated between arguing with her mother to stop "nagging" him, getting angry with her father over his "nastiness", and withdrawing completely and spending time away from home.

As. Mr. Polski pushed to finish building his home, his chest pains increased to the point where he was taking over ten nitroglycerine pills a day. He said he took his frustrations out on his wife. "I get aggravated and I do take it out on my wife...It is only when I'm working, doing something and I'm bothered. It is bothering me to get these pains. It is such a simple thing and I can't do it anymore." His wife who earlier had seemed satisfied with the recovery process, greeted me one morning in the following manner: ES: (as I arrived), How are things? Mrs. Polski: (shaking her head and laughing sorrowfully)"He hasn't been feeling too good. He has been so cranky. I feel sorry for him. But what can I do? He yells all the time." (she begins crying).

Another wife, Mrs. Ambrosio, told me at the time when her husband started becoming more active: "I think I am really getting on his nerves the last few days. Really, it has not been too good. (ES: Why is that, do you think?) "He feels that I am telling him too many things. He is really getting uptight." She went on to describe a fight they recently had in which "he really blew his top" and said things to her which upset her greatly.

A difficulty all these families faced was a lack of being able to predict what the patient-husband would do next, and when hostilities would emerge. The patients themselves were not sure what they should do or could do, and how they would feel afterward. They advanced toward normalization filled with uncertainty. They seemed often to have no systematic plan of recovering past activities and often made spur-of-the-moment decisions. For the wives, this meant that they could not organize their time, as some of them had before, to be present to counsel and help when their husbands were likely to be active. Some reported that they went out only to find that the men had done some large task. Mrs. Ambrosio, for example, found that her husband plastered the ceiling one afternoon in her absence. This precipitated an argument. She resolved to stay home as much as she possibly could.

This normalization period was characterized by lack of trust. People could not count on each other to behave in accordance with one set of norms. Shocks became commonplace. Mrs. Stein said: "I never know what kind of a mood he is going to be in when I get home." Patients, on the other hand, accused their wives of blaming them without cause, and treating them like children.

Although each of the five families were confronted with the same problem, the struggle to deal with it took different forms. Again, family structure and value climate seemed to predict the mode of problem solving that followed.

I Normalization in Role Exchange-Low Companionship Families

The tendency for the husbands to increasingly take on tasks within the home without regard for either wifely or medical advice made it exceedingly difficult for the wives to remain involved in the recovery process without directly opposing this behavior. They still felt an obligation to help prevent the reoccurrence of illness, and perceived their husband's present behavior to be dangerous. When they did try to intervene, however, the result was often conflict.

Since a part of the wife's strategy included staying aware of her husband's behavior in order to try to persuade against overactivity, the times when she felt constrained to argue with him increased steadily. In addition, the higher level of activity was seen by the wives as directly related to increases in symptoms which the men exhibited. Mr. Stein had severe chest pain and required rehospitalization. Tests revealed that blood clots had formed in his legs presenting the danger that one would eventually lodge in the heart. Mr. Polski's chest pain increased steadily and he took large amounts of nitroglycerine to control the pain while he worked. Mr. Asti felt "burning" in the chest.

The wives struggled briefly against the activities of their husbands. For a time the role-exchange homes were conflict ridden. Then the role-exchange wives disengaged once again from efforts to control their spouses' behavior. Up until the time this study ended, a process of withdrawal of the roleexchange wife from the recovery process took place. Unlike her first disengagement at the start of the second stage of home care when the wife remained committed to playing a role of influence in her husband's illness management decisions, now she seemed to give up any claim she might have had to an influential voice in the care.

The withdrawal of the wives was begun by redefining the situation in two ways: First, by decreasing their opportunities for observing "deviant" behavior; second, by transferring expertise, that is, by assigning full responsibility to the men themselves for interpreting and implementing the recovery process.

During the period when the role exchange men were moving toward normalizing their lives, their wives also took important steps to resume their own pre-illness lifestyles. As a consequence, they spent more time outside the home, and refocused their attention when in the home. Mrs. Asti resumed her recreational activities which included playing cards at friends' homes, going to the racetrack with them, and regular visiting with friends and relatives by herself. She also began special housecleaning projects which absorbed several daytime hours. Mrs.Polski also made arrangements for visiting and shopping trips with her friends. Steadily her own interests took the place of her concern with what her husband was doing. I asked her if she was still involved with trying to limit her husband's activities. She replied: "I ask, but I can't wait around all day." Mrs. Stein told me she tried to act like "like everything was OK". She did this by trying to attend to her sewing and reading when she came home from work, and by not insisting, as she had done earlier, on serving her husband dinner.

The interviews during this time reveal a change in the wives' answers to questions about patient knowledge of the medical regimen. There was a tendency now to emphasize what the patient knew, as opposed to what they, the wives, knew. Before, not knowing in detail how the patients were expected to behave was not perceived as a barrier to giving advice (one wife said earlier, "I really don't know (the details of the regimen), but I want him to rest as much as possible".) Now, not knowing the details was given as a reason not to try to act and change their husband's behavior. After Mr. Asti started doing activities which were considerably more strenuous than those he had been used to doing in Stage Two, I asked his wife what she thought his activities should be in his condition. She replied differently than she had earlier to a similar question. Now she said,"I don't know. I guess if he feels like doing it it's alright." I followed up: "Do you have to keep after him for what he does?" She answered: "Not as much. He knows what to do, he doesn't need to be told."

Other wives also began to make statements indicating that the major burden of responsibility for the care was held by the men themselves. I asked Mrs. Polski if she believed that the physician should have reprimanded her husband for his violations of the medical regimen. She replied, "No, he doesn't need to be told, he knows when he doesn't stop he has pains. He's a big boy now."

The decrease in wifely protest did not completely defuse the volatile situation in the role-exchange homes. The men were still capable of expressing their inner tensions through hostile words and deeds. Their wives reacted by further withdrawal, not by reciprocating the anger as they had done before. Mrs. Stein said:

> He gets very upset with me. (ES: Is that different than before?) Yes, I talk loud. I cannot modulate my tone. I happen to be the type of woman who has a loud voice. I'm trying very, very hard to speak softly. Lots of times when we are talking he tells me, 'What are you hollering for? Icannot even talk without you hollering'. I said, 'I'm not.' He said, 'Oh yes you are.' So there is that conflict that I never had with him before. He knows my tone of voice...(ES: When he says things like that how do you respond?) I tell him I'm sorry That ends it then and there. I'm sorry.

Mrs. Polski said that she always knew when her husband was in pain because he was "cranky and irritable". She said that his behavior prevented her from talking much to him: I'll say: 'Let it go. You did enough for today.' He gets mad. I don't say anything. I walk away. I ease my conscience by telling him to take it easy, then it is up to him...When he hollers I shut up. It would only drag it out."

As we have seen, in role exchange families, once the husbands demonstrated that they would no longer compromise with their wives, the nurse role the wife had been playing became no longer viable. As Goode[8] points out, the person faced with a choice over conflicting role demands will be guided in his decision depending on which of the competing roles offers the most in the way of rewards. In role exchange families, individual's separate needs and interests were usually given preference over the demands of the family unit. The men were determined to no longer be limited in pursuing their own interests by the expectations of others in the family. They called upon their right to be autonomous. For the wife to force a choice between her demands and those emanating from the man himself was to set up a self defeating situation. Wives seemed to realize that they could not continue to demand that the men accept and/or comply with their interpretation of the illness and care without serious conflict resulting.

People often attempt to coerce a certain standard of role behavior by threatening punishment for non-conformity. These wives had few negative sanctions they could apply. From the man's point of view, the punishment that the wife could threaten (loss of affective support, or discontinuance of services in the home, for example) would probably have less of an impact on him than the loss he would experience by non-participation in his non-family world.

Another negative consequence which would have derived from a role-exchange wife's insistance on playing a nurse role would have been her own loss of ability in meeting her own personal needs, including the mobility to engage in extra familial relationships.

There is another. Were she to continue to accept responsibility for preventing the man from engaging in potentially harmful activities at a time when he was increasing such activities she might feel a share of blame if harm did befall the man. She would be in the position of retaining responsibility for his survival without the means of constraining her husband from what she considered to be dangerous activities. Thus, she transferred this responsibility to the man, and extricated herself from situations where she could observe, and thus feel obliged to interfere. There was nothing to be gained, but much to lose in remaining in the nurse role.

The paths the family members took in the face of this conflict were familiar ones. As we pointed out in chapter four, in role exchange- low companionship families, interpersonal differences tended to increase social distance among the members. The value orientation stressed that individuals had the right to expect considerable amout of freedom over behavior. The choice of what to do and when to do it was wide, interference was minimal.

II Individual Differences in Role Exchange Family Behavior During the Normalizing Phase

Transferring responsibility to the husband while reengaging formerly satisfying life patterns was not accomplished with the same amount of ease in each family. Individual differences in how families stabilized their behavior patterns seemed related to the following sets of circumstances:

1. If the man's health improved and did not show signs of deteriorating under his lifestyle, and his wife was successful at normalizing her own social life, the family was able to function smoothly. The crisis appeared to be over. (The Asti')
2. If the man's health deteriorated under his lifestyle, yet the wife was successful at normalizing her own social life, interpersonal conflict, while present, was kept within tolerable limits. (The Polski's)
3. If the man's health deteriorated, and the wife was unsuccessful at normalizing her own social life, family life was severely disorganized. The family crisis deepened. (The Steins)

II (1) Emerging From Crisis - The Asti Family

Like the other role-exchange families where the men were determined to leave the sick rôle behind, the Asti's lived through a very difficult, conflict ridden period. Neither spouse was confident in returning to normal, pre-illness patterns. Mr. Asti approached each new activity with a dread of what the consequences would be. Feeling discomfort in his chest did not restrain him from doing more, it just made him more anxious. To his wife, he still appeared unwell. She said he was pale, and his eyes didn't look clear. Her memory of friends and relatives who had died from heart attacks was a constant reminder of the need for her husband to be cautious.

Mrs. Asti tried to compensate for reducing her own involvement in her husband's care. She tried to induce her married daughter to substitute for her, and she continued to call upon relatives to volunteer their help in chores. Neither made much of an impact on his pace.

As conflict continued to emerge even after Mrs. Asti refocused her attention to her own activities, she was instrumental in keeping the members of the nuclear family from confrontations. She urged her children not to respond when their father seemed to provoke arguments with them. What she in effect told them was - Listen, and then ignore him. He had become uncharacteristically invasive of his children's privacy and critical of their behavior at home. He yelled at Rose for not cleaning her room, and for not responding quickly enough to suit him when he asked her something. Mrs. Asti also urged her husband not to pay attention to what the children were doing.

The children, who were accustomed to spending a good deal of time away from home, and when at home, to be by themselves, managed to increase their separateness even more. John, it was reported, was not around as much as he normally was. Moreover, he seemed to avoid occasions of friction with his father by refraining from requesting favors such as borrowing the car. I was told that prior to the illness, refusal to let John borrow the car led, occasionally, to arguments with Mr. Asti. Rose's strategy was to spend more time at the home of her boyfriend, or in her own room. She also assiduously avoided answering her father back. There was also a noticeable decrease in interaction between Mrs. Asti and her daughter Rose.

Lack of intrafamily interaction and withdrawal of the members into theirown personal worlds did reduce the occasions for conflict without creating a serious problem in terms of feelings of mutual hostility or estrangement. Family members told me they believed this was the "best way" to protect themselves from conflict and defined the withdrawal and avoidance as mutually beneficial.

No one seemed to blame Mr.Asti for his bad moods. Mr. Asti's wife and children spoke of the reasons he had for feeling and acting irritably. They blamed the situation and felt these moods would pass. In the meantime, they would continue to give him a wide berth.

Mrs. Asti left her husband to himself and went about her own business in and out of the house. Prior to this point in the homecare period , she stayed home more than usual. She had even rearranged her weekly card game with her friends so that they gathered at the Asti home where she could keep her husband under surveillance. Now, however, the game returned to her friend's home where they always met prior to the illness. For the first time since before the illness, she also went to the race track on weekday afternoons, leaving her husband at home. Her role in the care narrowed to control over the diet. She continued making all his low sodium, low fat meals. When I asked what her involvement was in the care, her response was almost exclusively in terms of diet. She seemed to build up this role and defined her responsibilities almost totally in terms of trying to effect a weight loss in her husband. Whereas in earlier interviews, she told me an assortment of areas of care which concerned her and which she was directly involved in. Now she spoke only of the diet.

Conditions in the family changed dramatically following an examination of Mr. Asti by a physician affiliated with his union. Mr. Asti's union required its sick members to consult with one of its own physicians for clearance either for return to work or for continuance of sick leave benefits.

Two factors made this a "landmark" experience for Mr. Asti. He said the doctor was an "internist", someone who he believed had special training in the area of the heart. As such, his credibility with Mr. Astiwas considerably higher than the family doctor's. NeitherMr. nor Mrs. Asti perceived the family doctor as highly knowledgeable in treating heart attacks.

This physician's approach seemed particularly suited to Mr. Asti's needs. He reviewed his activities and then told Mr. Asti to <u>do more</u> than he was already doing. "He took the fear of doing too much away from me", Mr. Asti reported. The way that Mr. Asti described their meeting, the doctor presented an active, authoritative image which was convincing. The doctor discounted Mr. Asti's fear about the "burning sensation" in his chest. His own family doctor had told him not to worry about this in the past. Yet, for over a month in every contact I had with Mr. Asti, he expressed concern about it, and anxiety over his schedule of activities.

When I observed the change in Mr. Asti's morale subsequent to this examination, I realized how deep had been his worry. The internist said not to worry and he seemed to believe him. Mr. and Mrs. Asti took a week's vacation to Florida and reported it was a happy time. For the first time, Mr. Asti was able to reduce his weight, which the couple thought was remarkable since in Florida the relatives they were visiting prepared special Italian style meals, rich in sauce and pasta. Somehow, as his morale went up, his weight went down.

The family came together again - within their normal boundaries. Mrs. Asti even asked her husband to help her with some chores around the house. Mr. Asti was looking forward to returning to work in a few weeks. Rose said that she went out now when she wanted to , and since her father was no longer "nasty" she felt no need to stay away from home longer than she wanted to. There was no evidence that the conflict the family had recently experienced had left any bitter aftermath. Indeed, the value of their problem solving techniques seemed to have been confirmed in their eyes.

Looking forward toward the future, Mr. Asti said he would "slow down" a little. For example, he planned to save his heavy household chores for weekends rather than starting them after work. But, he indicated that life for him and his family would go on as normal.

II (2) Conflict Tolerance - The Polski's

During the second stage of the home care, the relationship between Mr. and Mrs. Polski had been amicable. Both were optimistic about his health, and the couple was able to play their respective roles of patient and nurse with flexibility. The climate in the home was shattered by a serious intensification of symptoms of illness after Mr. Polski increased his activities. Rather than reduce the extent of work building the house, Mr. Polski increased his intake of nitroglycerine, which sometimes went as high as over twenty a day. As soon as the pain subsided, he went back to work.

As the other wives had attempted to do, Mrs. Polski tried to stop him from working. Her arguments and direct efforts to intervene by helping him get done faster so he could rest were almost complete failures. Both spouses were candid about the extent to which they were drawn into conflict over this issue. Both realized that he would not reduce his activities, and planned to increase them. Even when she said she withdrew him, she claimed, and he agreed, that hostilities continued to beset them. "I want to do as much as I can for him, but he never talks nice to me. He is always yelling. I can't seem to please him." Then she reasoned: "It's not going to stop. I have to get used to it. <u>One of us has to give.</u>" (my emphasi

Mrs. Polski was the one who gave in. First, she fled at the first sign of conflict. She did not completely stop expressing her opinion of the "correct" way of recuperating. But when her husband responded in anger, she was silent. She told me she refused to respond once he became angry, but walked away, leaving him alone. There were certain elements pfpassive-aggression in this since she said Mr. Polski would have welcomed an argument to release his own tensions. She realized that walking away sometimes made her husband angrier. But Mrs. Polski claimed that she could not bear the constant arguing. She herself paid a price. She told me, "It's hard to hold it all inside."

It was at this point that Mrs. Polski returned to a very important part of her life - visiting her friends in the city. Since the start of the illness, she had not taken her usual long visits to the city. During the optimistic and amicable part of the home care, she claimed she had an obligation to stay with her husband. She explained then: "I'd feel terrible if something happened when I was away." Making the decision to leave her husband for the several days these trips lasted took into consideration her feeling that: "There is nothing

I can do here." She told me that her husband was aware of the risks he was taking and was not uninformed of the fact that his family doctor had recommended that he do less, especially in light of the chronic pain. "He doesn't need anyone to tell him," she said, "he knows when he gets pain he should stop."

Going into the city was a great lift to her morale, "Thank God for my friends,"she exclaimed. She did not completely stop responding to his pain or suggesting at times he should do less. But she was able to choose the occasions to do this, and being away more they fought less, and she seemed to be able to maintain a satisfying life. When we spoke of her experiences with her husband, she showed her disappointment at his declining health and she cried over how she felt about the conflict. But when she recalled the typical events of her day, she perked up and seemed for a while to forget the bad times in the home as she told me of the good times outside, in the country and the city.

While Mrs. Plski resumed her life with her friends, Mr. Polski worked to finish the basement of the home in the country. He worked as long and as hard as his pain and fatigue would allow. Withthe help of nitroglycerine, he continued heavy construction work until his death from a sudden heart attack, about five months after first entering the hospital.

Mr. Polski was aware that his doctor wanted him to cut down, not increase his activities. This wasnot acceptable to him. He said he would prefer death over "living as an invalid. He perceived no middle ground between full activity and invalidism.

Not being up to full strength was frustrating to him. During a visit to relatives where for several days he did very little activity, he said that he was discontent even though he did not have to take nearly as many nitroglycerine pills.

During one of our conversations, I asked why he was ignoring the pain. "Why be so active when it seems to make you feel worse? Wasn't it the better thing to lay off for a while, or do less/" My questions mirrored those the wife had been asking. In answering, he became somber and said thatif he did not work he would lose all will to live. He pointed to the containers of medication on the table and said that he would stop taking them, and moreover, would not stay on the diet at all once he felt he was not being productive. Working, being active, gave his life meaning.

II (3) Continuing Deterioration - The Steins

During the second stage of the home care, Mrs. Stein had a forewarning of the negative consequences of trying to control her husband's behavior. So when he arrived home from the hospital the second time, she took only a day or two off from work to be with him, as compared with over a week after the first hospitalization. Also, she told me she was very hesitant to express her opinion of how her husband ought to behave: ES:"What about when he came home from the hospital the first time?" Mrs. Stein: "I was overly protective." ES:"What taught you that?" Mrs. Stein: "Because he was getting annoyed with me...if he dropped anything, I went to pick it up. I have a bad back so I have to watch how I bend. That I know was annoying him."

When I observed the couple together at home, I could readily notice the tension between them. As we sat together over coffee, they seemed unsure of what to say to eachother and how to say it. Deciding who would serve coffee, for example, sometimes resulted in brief but sharp exchanges between them. When Mr. Stein left the room for a moment, his wife just lowered her eyes and shook her head. Often she would say to me: "I never had this with him before."

Even with Mrs. Stein trying to stay uninvolved in her husband's affairs which included taking medication to dissolve his blood clots, the couple was together considerably more than they had been for the past few years. This had been due to their very different work schedules. Now, instead of only spending weekends together, they were both at home every weekday evening. Mrs. Stein told me she had expected that being together would be a mutually rewarding experience because their weekends before the illness had always been pleasant.

Things did not work out as she expected. She perceived his health as steadily deteriorating, and believed his actions were to blame. Sometimes, as she told me, she "just had to" express her concern and her anger. For example, Mr. Stein was smoking two packs of cigarettes a day, driving the car, and making repairs in the house which involved climbing and lifting heavy objects. When she argued with him to cease these activities, he accused her of treating him "like an invalid." When she refrained from trying to intervene, she worried. The fact that she could have so little impact on his behavior was a source of continuous personal grief because in her view, he needed someone to guide his recovery. She expressed her problem to me this way:

> I'm very short tempered with him which is very bad I know...I have very, very guilty complexes - the fact that I have to leave him alone. The fact that I tried to interest him in something and it didn't work. The fact that he climbed up and changed the light bothered me. He did that when I wasn't here. He stood on that chair. Now, God forbid, had he fallen off or something, that bothers me A lot of things are bothering me.

Ordinarily, she did not want to inquire about the outcome of various tests he took to determine the extent of his blood clotting problem. It was inevitable that she would learn, however. When she did and the news was bad, she could not control the emotion she felt. Sometimes she learned new dimensions of the illness when her husband told me about them. On one occasion he told me, in her presence, some particularly disappointing news. The lab result indicated that a danger point had been reached. To control the clotting he was required for the next few days to take such a high dosage of medication that there was a danger he would suffer internal bleeding. When Mrs. Stein heard this, she bolted upright in the chair and a look of worried concern covered her face. A few moments later, she left the room and did not return. Mr. Stein then observed that his wife was quite unable to bear up under such news and that he had to censor the statements he made to her about his health.

Managing the bad news was a source of strain to both persons. His knowledge that she could not tolerate it led him to mask it. When it was revealed it came to Mrs. Stein as a shock. Mr. Stein indicated he felt under-supported. He asked: "What would happen if I have an emergency at home? Who would be able to take charge?"

Other role exchange wives were able to reactivate their outside social groups and interests and so were somewhat shielded from trouble inside the home. Mrs. Stein's chances for this were hampered. She still went to work, but at home could not engage easily in the activities which normally brought her satisfaction. She said that after work:

> There are times when I don't want to see anybody, hear voices. I don't even want to pick up a phone. I'm with people five days a week, eight hours a day. All I do is talk, talk,talk. There are times on the weekends I don't want to see or hear anybody. I want to come in, close the door and just forget. Now, it's different. Now he seems to get tense as the evening wears on. If I ask him something, he'll just give me a dirty look.

It seemed that a major source of strain was the fact that neither person could give to the other the support that was desired. Mr. Stein felt his wife was not competent to collaborate with him on ways of managing his illness. She seemed unable to hear "bad news" without becoming upset, she seemed to him to lack knowledge and skill to prepare his diet properly. She also seemed to him to be uninformed about the regimen. She also did not support his decision to do as much as possible in spite of symptoms. Her arguments against his activities were perceived as another burden he had to cope with. Mrs. Stein claimed she could not win the concessions from her husband which would have given her a feeling of constructive involvement in his care. When she tried to rekindle the affection which she had known before the illness, she claimed he refused to reciprocate. Finally, she could not withdraw to the comfort of her separate lifestyle. In the midst of these problems, Mrs. Stein suffered a heart attack and died.

III Normalization in Role Differentiated Families

Mr. Grasso and Mr. Ambrosio first emerged from a sedentary, patient oriented mode of behavior to an active, task oriented one at times when they were least likely to be observed by their wives. They began attempting arduous activities,and returned to premorbid habits like smoking, drinking coffee, doing chores secretly. This stands in contrast to the openness with which role exchange men behaved. It illustrates an important difference in the organization of the home care in the families which relates dirctly to family structure and value climate. It also suggests differences in the manner in which role differentiated couples tried to resolve problems generated by normalization.

When Mrs. Grasso and Mrs. Ambrosio learned that their husbands were acting one way in their presence and another when they were alone, it created a serious practical problem. The two wives had to re-evaluate their strategies for managing family affairs and maintaining control of the recovery process. The pattern which they had evolved during the second stage of home care seemed less than adequate now. The wives immediatly rescheduled their time so that they could more effectively observe and limit their husbands' behavior. For example, when I asked Mrs. Ambrosio about her activities outside of the home like shopping, visiting friends, and so on, she replied: "It doesn't work out. When I come home I find that he has been doing something that he is not supposed to do, like plastering. He did the porch ceiling." Mrs. Grasso, who was employed four days a week made it a practice of stopping by the family store on her way home to be certain that her husband was not lifting heavy objects, and was sitting as often as he could. She also received information from a clerk who worked in the store.

This strategy of trying to induce conformity by observation of the husbands[7] not only complicated the womens' daily routines, but also led to a climate of distrust in the homes. The men reported that they resented the extensive questioning they were subject to when the wives came home. At the same time, they felt the need to expand their activities. It was common for the men to seek ways of avoiding their wives. Mr. Ambrosio told me:"I've got to fix a fixture over there in the hall, the light went out...That means getting a ladder out in the garage. Now I know that my wife is not going to let me get the ladder, so I may not be able to do it until she is not around." Mr. Grasso's son, Anthony, told me that he noticed that his father was taking precautions, like keeping the front door locked so he would have time to dispose of evidence that he was smoking or working before anyone came into the house.

On the other hand, the men told me that they suspected their wives were deliberately misconstruing the physicians' instructions. The following is illustrative: E.S. "Did the doctor give you a date for driving?" Mr. Ambrosio: "He didn't give me anything." E.S.:"Ithought you said the middle of April?" Mr. Ambrosio: That was Dr. J. But I have a sneaky feeling that my wife is going to put that off no matter how well I plead my case...When I get through with him: 'Fine." Everything is presumably ok:'You are doing well, keep up the progress.'" E.S.: " Then she will go in?" Mr. Ambrosio: "He will say to her,'Do you have any questions?' Then she comes out smiling, and I say: 'What happened?' She says, 'Oh fine'. Then we get home and for a day or so she won't let on what happened."

Wives who valued role differentiation accepted physician-approved increases in husband-patient activity grudgingly. I asked Mr. Grasso how his wife reacted when the family doctor told him he could return to part-time work in the family's store. "She can't say anything about it. She doesn't like it but she has to go along because the doctor said it was OK."

Nor did the wives make inferences from what the physicians had approved. Whatever was not explicitly sanctioned, the wife considered not approved. Mr. Ambrosio was allowed to walk up to a mile a day. Yet his wife continued to insist that she check the weather conditions before he went a few blocks to get the morning paper. She also would not cooperate when he wanted to share small chores with her. She continued to discourage going up and down stairs. The men, on the other hank, argued that since they were allowed to walk long distances, or work part-time, they could also become active in other areas, especially engaging former household responsibilities.

In attempting to hold back the progress of the man toward normalizing his social behavior, the wife who valued role differentiation and intrafamilial companionship was at the same time keeping herself from returning to certain elements of her premorbid lifestyle. Each wife had additional household chores, and less time for her own personal affairs. In addition, as the men became more adamant about defining for themselves the parameters of the recovery process, the wives also had to deal with an increasing amount of hostile opposition from the men. When we look back at how the other wives , those who valued role exchange and extra-familial social involvement, attempted to withdraw from participation in the recovery process in a similar situation, a very significant difference in the orientations of the two groups of wives clearly emerges. At a point, where the wives who valued role exchange disengaged from the recovery process, the wives who valued role differentiation increased their efforts to remain in control.

It is difficult to overlook the fact that for the wife who valued role differentiation and intrafamilial companionship, normalization would mean that certain premorbid marital patterns which she disvalued would probably be re-established as well. In other words, Mrs. Ambrosio and Mrs. Grasso stood to gain if their husbands accepted as a consequence of the heart attack, some amount of permanent disability, and limited sick role status. This was precisely what these wives tried to convey, i.e. that the men were a long way from being well enough to return to the lifestyle they enjoyed prior to the heart attack. For a long time prior to the current illness, Mr. and Mrs. Ambrosio had been in conflict over how much each should be responsible for in the home and on what basis family tasks should be distributed. Mr.and Mrs. Grasso were divided in their opinions concerning whether to continue ownership of the family store. Now each wife anticipated a favorable settlement of these issues because of the illness. Since their husbands were inclined toward resuming fully their pre-illness activities, retaining control over the recovery was crucial to the wives' goals.

The conflict between the spouses which focused specicically on the definition of the illness and on interpretations of the medical regimen had implications of a wider sort. Control over the organization of the family was at stake. The outcome of patient rehabilitation would affect the nature of the marital dyad. The nurse role gave the wife more power and influence over her husband's behavior than she had previously.

This power could be used to alter existing marital patterns to her greater satisfaction. If the man returned to a full normalization, she would lose this leverage. In contrast, we saw that the role exchange wife did not value such additional influence over her husband's behavior. Family members who were less dependent on each other for instrumental or affective support tended not to seek control over their partner's behavior.

III (1) Emerging from Crisis Through Disability - The Grasso Family

The intensity of the crisis within the family, and the fact that it went unabated for about two months is indicative of the importance of the issues at stake for the Grasso family members. Mrs. Grasso perceived herself as fighting to preserve her husband's health. Butif he followed her direction, she would reap benefits as well. By selling the family business, Mr. Grasso would be able to spend more time at home, and there would be more time for the couple's social life. Potential financialloss, which Mrs. Grasso feared the store would result in, would no longer pose a threat. Mr. Grasso perceived himself as fighting for a valued self image as family breadwinner with a respectable occupation as well as playing a role of importance in household functions. This was threatened by his continuance in the sick role, and his wife's active nurse role.

There were times, Mrs. Grasso told me, when she felt great difficulty in sustaining her side of the conflict. She said she was worn out physically and emotionally. There were bitter disputes, and then long silences - what seemed to bother her the most was when her husband refused to talk to her. She said she sometimes tried to reduce her role and not fight with him about his activities around the house, and in the store, but she could not remain silent for long. She said it caused constant fighting but she had to "nag him". Her resolve to disengage did not last long. Shesaid that it caused constant fighting but "it means life!" This was, she said , the worst time in her entire married life.

When the family doctor gave permission for Mr. Grasso to return, part-time, to limited work in the store, the conflicts intensified. He became very active, he told me, and did much more than the doctor had specified. He said he could not just "sit around and be useless." His wife learned the extent of these activities by calling his assistant a family friend, who was sympathetic to Mrs. Grasso's view of heart attack recovery. She also came by the store herself and often saw him heavily involved. This was how she found out he was smoking cigarettes again. Their son described the bitter arguments which followed these occasions.

Most of the fighting between the couple was over whether or not Mr. Grasso would ever be healthy enough to return to full time operation of the business. He said yes, she insisted no. An early strategy he employed was to argue that he would suffer severe personal loss if he had to sell the business and then could not find a suitable job. He claimed that because of his two heart attacks, companies would be reluctant to hire him. This would leave only jobs like grocery store clerk and messenger boy open to him. He realized that both his wife and son knew how difficult menial positions like these would be for him to accept.

The appeal to his individual needs was not persuasive, however. His wife countered that the strain of ownership, and the long hours it entailed would endanger his life, and thus bring him and the family an even greater loss.

Anthony, their son, proved to hold an important key to the outcome of this problem. Since homecoming, he had been in the position of supporting his mother's approach to the care. He too insisted that his father be slow in resuming past activities, and became upset with his father's smoking, activity, and failure to take his condition seriously. This alliance with his mother caused Anthony some ambivalent feelings.[9] Historically, the family triad consisted of father-son vs mother. Anthony did not want to lose the close affiliation with his father. Yet, he felt obliged to oppose him when he observed his father disregarding a cautious approach.

It was Anthony who suggested that a compromise could be arranged by his becoming a partner in the business with his father. He proposed that the store be expanded with him doing the heavy work and his father retaining a less strenuous managerial role. Father would plan, son would implement. In this way, his health would be less threatened by the strain of ownership and operation. Although Mr. Grasso would have preferred the sole responsibility for the store, what his son proposed took away much of Mrs. Grasso's argument. He agreed to the partnership.

Mr. Grasso told me that the only way his wife would accept the store was if it was clearly an asset to the welfare of the family. Since it would provide a career for her son, he said, it now fulfilled this important criteria. The store could be defined as a family asset. Ultimately, after Mr. Grasso's retirement, full ownership would come to Anthony.

This new development caused Mrs. Grasso to change strategies. She still opposed the store, and wanted her son to return to college. Yet, without being able to argue against it on grounds of health, continuing direct opposition would appear selfish and a violation of family norms that differences be settled by compramise. Under these circumstances, Mrs. Grasso could not coerce, she was forced to persuade. She told her husband, "I leave it up to you... Whatever you and your son decide to do." But, as Mr. Grasso explained, "She keeps bringing up roadbleck questions, 'what if' questions." She took advantage of the closeness that she had recently developed with Anthony to attempt to persuade him to change his plans. She argued that the store would never provide enough income for two families.

Even though the decision about retaining the store was no longer one which Mrs. Grasso could claim in her role as nurse-surrogate, disputes over control of the home care continued unabated. The extent of his activities in the store brought continuous arguing, as did his activities at home. Could he go up and down stairs? How often could he attend social gatherings? Could he take his grandchildren out to play? Ordinarily an extraverted person, Mr. Grasso became uncharacteristically quiet and uncommunicative between fights. He sat silently for hours, not responding to his wife or son. When friends visited he said he sometimes went into another room by himself. He explained that his withdrawal from social activities and interaction was in response to not being able to participate fully. This angered him and he left the room rather than expressing his anger publically. It was during one of his silences that his wife threatened to leave him.

Mrs. Grasso must have been persuasive with Anthony because he did finally agree that expanding the store would not work. He abandoned his plan to join his father in the store. Anthony's decision not to participate in the store might have contributed to his change in orientation to other illness management issues, like smoking, and diet. He now became tolerant of his father's view. For the first time he agreed with his father that his mother was too harsh and too cautious. This initiated a period of conflict between mother and son. Anthony then increased his time away from home. He disengaged from the active role he had been playing at home. He returned to a full time job, and reactivated his social life, dating and seeing friends.

Both spouses perceived the growing threat to the marital bond. Mrs. Grasso showed no signs of weakening in her position, however. Mr. Grasso explained that he was faced with a choice-either to capitulate to his wife's demands or end the relationship. He opted for maintaining the marriage. The store would be sold. He put it this way: "This was probably on my mind: the fact that we have had many, many ugly disputes about this thing (the store) and I've already made up my mind to listen to her this time, just for the sake of peace. I don't like the bickering. I think perhaps even if I were making a good living, I don't believe busting up twenty nine years of marriage is worth that."

A short time after he made this decision, his wife found a job for him - at her own place of employment. It was a position Mr. Grasso found appealing and it did not require a medical examination. From this point until I stopped visiting the family, the climate steadily changed. Arguments were reduced. Mrs. Grasso said that she became more tolerent of minor deviations in activity and diet, and was less thorough in scrutinizing his activities. She did not complain about his smoking as long as he did not smoke in front of her. While the nurse role remained substantial, she carried it out in a less invasive manner. In my last talk with Anthony, he told me that during the preceeding week, "We laughed together again."

III (2) Normalization and Reemergence of Role Dissensus - The Ambrosio's

The "honeymoon" phase of the home care which this couple enjoyed while Mr. Ambrosio was a cooperative husband-patient deteriorated steadily as soon as he began to make progress in recovering pre-illness activities. When he replaced his wife who had been substituting for him during the hospitalization and the first two months after homecoming, the old conflicts over division of labor reemerged with a new intensity.

The first signs of change in approach to his patient role came when Mr. Ambrosio told me that every chance he got he was doing chores around the house without his wife's knowledge. She had become confident of his compliance, and began to leave the house more frequently for shopping and visiting friends. She still enjoyed running the house and expressed high satisfaction with her husband's passive role. While she did the chores, he engaged in crafts she bought him. She took it for granted that he would not deviate from the regimen she supported.

Because she was responsible for chores like shopping which required that she leave the house, Mr. Ambrosio had ample opportunity to test his endurance. He would start with relatively easy activities and gradually, but steadily, move to more demanding and to him more rewarding tasks. Many things he did, his wife never seemed to discover. But when she did and rebuked him, he responded angrily. This was a change.

There was a good deal of mutual disception in their interaction. Mrs. Ambrosio believed that her husband's expectations for recovery were overly optimistic. He expected to be given permission to resume most of his normal activities within three months. Nothing in his visits to the doctor seemed to dispell this expectation. Yet, his wife revealed to me that the doctor told her he would never be able to return to a full schedule of activities, and that it would be six months before there would be any significant change in his present activities at all. She said she was afraid to tell her husband this for fear he would rebell against the regimen entirely.

In an attempt to check his activities, Mrs. Ambrosio redoubled her efforts to get the chores done before he did. Before the illness, she had tried this and failed. She had the advantage now, because he had not yet recovered his full energy level. When she awoke one morning to find her husband already up with the breakfast made,she resolved to get up even earlier the next day. When he got up to do the dishes after dinner, she rushed to get them first. The following exchange provides another example: ES: "Tellme, you took the garbage out because you wanted to see -" Mr. Ambrosio: "I wanted to see if I could do it." ES: "And what did you see?" Mr. Ambrosio: "Nothing. I took the garbage out and I felt fine. But she is not going to let me do it...I know that on Wednesday night she is going to take the garbage out before I do it."

Each time that this occurred the anger and distrust deepened. I asked Mrs. Ambrosio to compare the demands of the home care at this point with the way she perceived them a month earlier. She said: "Then, when he was totally dependent on me I didn't have time to think....the strain was physical. Now it is a different kind of strain. It isa mental strain."

The conflict reached a new level as Mr. Ambrosio did more and more activity openly, without regard for his wife's protests. Telling me of his daily activities he remarked: "I'm up at first light now." I asked: "Doesn't your wife object?" He answered: "I just did it, I can't take the negative approach or nothing will get done. She screams at me. I say 'right' and go ahead and do it."

Mr. Ambrosio's decision to disregard the doctors' and his wife's advice took place at the same time he had communication with his doctor which emphasized the medical definition of his condition as still serious enough to require absence from most normal activities. He asked his doctor whether he could take a stress test at a local hospital - a series of exercises to test the capacity of the individual to engage in arduous exercise - given by a cardiologist. Mr. and Mrs. Ambrosio reported that the doctor replied, "No, I don't want to go to your funeral." During this same visit, Mr. Ambrosio told the doctor that he had been out that morning in inclement weather. The doctor was reported to have said, "you are crazy to go out in weather likethis." In spite of these warnings, Mr.Ambrosio increased the pace of his activities.

By the third month of home care, Mr. Ambrosio just about completely rejected his doctor's stated opinion that the heart attack still posed a significant threat. He told me: "Dr. M. keeps saying 'massive heart attack'. I just look at him and say to myself - 'I wonder if you guys really know what it is?' He had experienced no pain even with increasing his activities, and was on no pain medication. He began to describe his medical problem exclusively in terms of diabetes. He remained faithful to his diet, and regularly took his insulin. However, he also returned to near full activity.

Steadily Mr. Ambrosio was able to withstand his wife's efforts to control the pace of his activities. As his strength increased, he assumed more and more activity around the house. With this his wife's spirits plunged. When he was back involved in a full day of activities he seemed happy. His wife told me: "He wasked the car today. He was like a kid with an ice cream cone." Oblivious to his wife's attempts to slow him down, he painted part of the house, dug up the garden, moved heavy objects, transplanted large shrubs, and made plans for spring cleaning.

His wife once again found herself without control over his activities. She could neither persuade nor coerce him to reduce his activities. She realized it was only a matter of time before he recaptured most of his household chores.

Months earlier she had looked upon the changes which had occurred in their daily lives because of the illness as positive ones, they enlivened her life and created a positive self image for her. At that time she told me that her husband had learned to have confidence in her ability to play an active household role. Her perception was that he would henceforth divide household responsibilities. The prospect of this gratified her greatly. She said then, "My image has increased in my eyes too, because a lot of things he wouldn't let me do. I think I felt frustrated. That was why half the time I was getting involved in so many things because I don't think he gave me credit." During that part of the convalescence when Mr. Ambrosio's activity was limited, Mrs. Ambrosio discovered that she was capable of successfully running the home, including taking care of her husband's needs. When he depended on her she responded and it satisfied her. She realized how much she needed a significant role, and how important it was for her that Mr. Ambrosio accept her assistance and partnership.

Now, she realized that these aspirations would never be fulfilled. At one point she said, "I want to feel that he needs me." She never returned to her community work. Our conversations were suddenly terminated when she suffered a nervous breakdown and had to be hospitalized.

In all the families, the effort to resume normal social functioning began as a unilateral decision on thepart of the husband. The way the wife responded seemed to be determined by her assessment of the costs or benefits to be derived from the loss of her nurse-surrogate function. Noticeably absent from both the decision making process of the man, and the response of the wife was any significant input from the health care system. While each patient maintained physician contact through periodic visits which the patients themselves initiated, little or no guidance in solving the difficult problems being lived through on a daily basis was obtained. It was not unusual for a wife to accompany her husband to the doctor's office, or even be present during part of the examination. Sometimes in these meetings, the wife or the patient himself revealed that the recovery was not proceeding smoothly, that pain was accompanying activity, or that the level of activities went beyond what had been advised at the last visit. When this occurred, the physician advised the patient te be cautious and to do less than he was doing. However, these admonitions had little effect on men who perceived the regimen as depriving them of a level of activity consonent with their conceptions of an adequate quality of life. More typical, however, was that the patient asked few questions of the physician whose examination touched the physical aspects of the case solely, and whose advice for living with the ailment remained generally non specific.

With the interpretation of general remarks such as - Do a little more but continue taking it easy - left up to the patient and his spouse, the management of the recovery process became highly responsive to individual and family dynamics. The physician's participation in the home care was significantly outweighed by family values and social structure. The reasons behind the tendencies of Mr. O'Shea and Goldberg to postpone indefinitely many of their pre-illness activities were linked to how they and their wives perceived the consequences of normalization for health and for the marital relationship.

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Chapter VII

Conclusion

The findings of this study demonstrate the importance of family structure and value climate in coping with home based recovery from heart attack. While there were numerous problems and conflicts which confronted almost all the eight families, theway these were worked through depended very much on the structure of family living arrangements. Hill[1], Hansen and Hill[2], and Parad and Caplan[3] have argued that the quality of a family's response to crisis depends to a large extent on how the members define the situation. I have found this to be true in the families I studied to the extent that the disruption in relationships caused by the illness had different meanings within the study group of eight families. Moreover, I found that there was an association between family life-style, what the illness meant to the couples, and how they coped with it.

By definition, a crisis is a time of disruption of normal patterns of living. Disabilitating illness causes important structural changes in the family. Individuals acquire new functions, usual routines of daily living are interrupted. New roles bring novel and often unexpected personal and interpersonal experiences. What people do by way of coping with crisis induced changes in family routines and relationships depends on how they perceive, interpret and feel about them. Also, the extent to which members of a family agree in their assessment of the changes in living arrangements will have a significant bearing on the experience of the family in crisis.

In analyzing the factors responsible for the association between family structure and value climate, and the approach taken to managing the home care, one needs to consider the meaning of family life to the individual members. For it was clear that a significant portion of the actions taken during the post hospital period were directed toward preserving or improving the bonds which connected the members to the family. Even during a crisis, maintaining a family routine which satisfies the way that members wish to be together and apart seems to be anecessary family task.[4]

In Role Exchange - Low Companionship Families, changes introducted by the illness were antithetical to patterns of living valued by the members. They called for a high degree of interdependence and reciprocity. The husband as patient and the wife as nurse formed a closely connected dyad. Instead of flexibility and freedom of choice, which was an integral part of pre-illness living arrangements, husband and wife were now greatly limited by the confines of their respective therapeutic roles. This arrangement placed great limitations on the wife's ability to maintain her relationships outside of the marital dyad and nuclear family. As long as she felt obliged to pay more attention to her nurse-surrogate activities than to those in other spheres of life, she was denied experiences which were highly valuable to her. The closeness which the illness brought to role exchange coupleswas not desirable because it upset the balance on which the marriage was based.

It was this orientation toward separateness and individual autonomy which contrasted so sharply with the highly differentiated and reciprocal roles of patient and nurse-surrogate which the role exchange couples adopted initially in the post hospital period. It is not surprising, therefore, that the patient-husband and the wife-nurse surrogate would both experience strain from the antithetical expectations. And when the strain led to interpersonal conflict, the response was to redefine the situation in such a way that the couple could move toward a more congenial style of relating. In this context, the illness threatened family ties because it required members to play roles which were negatively valued. It explains the early willingness of role exchange members to withdraw from illness roles. Men in role exchange families were the first to resume pre-illness activities, and their wives sought to normalize their own social lives more rapidly than wives in other types of families.

Withdrawing from the roles of patient and nurse-surrogate to ones based on pre-illness values and expectations was highly dependent on how the state of the husband's health was perceived. Continuing illness, symbolized by symptoms of pain, fatigue, or depression, made it difficult for the wife not to attempt to intervene in her husband's decisions with regard to his lifestyle. The more this happened, the greater was the potential for interpersonal strain and personal anxiety. No one benefited from the change in living arrangements which followed the illness, and all role exchange family members had a stake in the rapid progress of the recovery process. An illustration of the importance of this is given in the cases of families where as the husband's health deteriorated, the marital relationship underwent serious strain.

Given these circumstances,I have observed that in families which fit the role exchange-low companionship type which I have described, there is a built in bias toward accentuating the favorable aspects of the recovery - to look for signs indicative of health.Reciprocally, since illness and marital disharmony were so closely entwined, it would seem that signs indicative of continuing illness would be avoided where possible, or,at least, minimized.

One cannot help noting that the management of the recovery process from a medical care system standpoint did not contain mechanisms for controlling the influence of bias or selective perception on the family's interpretation and operationalization of the medical regimen. The advice given to patients and their spouses was non-specific, and follow up,which was generally left to the initiative of the families, did not include a detailed probing of the rationale people used to make decisions to increase or decrease their activities.

People were left on their own to decide what specific activities and role behaviors fit within the general guidelines laid down by the general practitioner. Given this choice, members of role exchange families opted for a liberal interpretation which had the latent function of harmonizing interpersonal relationships. It bears repeating that where the course of the illness did not allow members to disengage from roles of patient and healer, the consequences for marital stability and emotional adjustment were disasterous to role exchange families.

In the four families in which at least the wife valued a role differentated division of labor, and sought a high degree of companionship within the confines of the nuclear unit, the changes brought about in family living arrangements were not entirely experienced as oppressive. Consequently, there was less urgency to withdraw from roles appropriate to illness.

Secondary gains accrued especially to role differentiated wives during the recovery period. This must not be interpreted to mean that wives did not suffer significantly from the increased burdens placed upon them, ordid not wish for the eventual recovery of their husbands. The point is that the changes in the marital relationshipand in some of the patterns of activity were perceived as positive and ought to be preserved for the benefit of the marriage.

In contrast to the value role exchange family members placed on separateness and individual social participation outside the home, the wives in all role differentated families strove for connectedness and joint social participation. The changes in lifestyle brought about by illness were perceived by the wives as conducive of intensifying connectedness both in and out of the home. This was especially true in the two families which prior to the illness had experienced frequent conflict due to a dissensus of opinion between husband and wife around the value of role differentiation and connectedness.

In spite of periodic opposition from their husbands, who did not always accept without reservation the wives' attempt to control the rehabilitation decision making, wives persistently strove to maintain an effective nurse surrogate role. With this function, they had major imput into the activities of the men and gained substantial control over the organization of the household.

As was pointed out in the earlier analysis, the family was the prime source of need fulfillment for people who valued role differentiation and close companionship ties within the nuclear unit. Thus the behavior of each family member was exceedingly important to every other member. More so than was the care in role exchange families where members were not as dependent on others for instrumental emotional support. For this reason, the chance to increase one's influence overother family members would be more highly sought in role differentiated than in role exchange families; and during the recovery period, the nurse surrogate role provided this opportunity. One could postulate, therefore, that there would be a tendency to use the illness to make fundamental changes in the family's living arrangements.

This explains the fact that in role differentiated families, the most severe interpersonal difficulties happened when the husbands wanted to discard the sick role and return to normal role functioning. The wife refused to withdraw, as her role exchange counterpart had, from her nurse surrogate role. This discrepancy in expectation fostered marital discord. On the other hand, when the husbands accepted the limitations on their activities and behaved as though they were sick, the families were conflict free and relationships were warm. It is not surprising, therefore, that with the wife in control of home care decision making, the pace of the recovery tended to be slow when compared to families in which she took a subordinate role. Signs of illness would be accentuated and those of health played down.

If what we saw in the families in this study holds true in many others faced with a home based recovery period following myocardial infarction, it would seem advisable to reexamine existing rehabilitation procedures. For when management of the home care is left so exclusively in the domain of the family, as was true in the cases we examined, the potential for rehabilitation may be limited by family values and practices. We saw that for one type of family,illness brought secondary gains to some members. While in others a rapid return to pre-morbid activities was highly desired. Under these circumstances, there will be a tendency to either seek to hold onto illness, or to reject it. In either case, the danger exists that rehabilitation will be either slowed down or prematurely accelerated.

In several families, it was clear that conceptions of rehabilitation goals often clashed with the realities of the marital relationship. Thus, members faced a hard choice: whether to persist in what was thought to be required for optimal recovery or to adjust one's expectations for the sake of marital harmony. This made the home care highly disturbing emotionally to individuals and to their family relationships. Moreover, it created a situation in which the good of the whole group was seen to be at odds with the goals of therapy.

Whether or not the behavior of the family members during home care would have been significantly altered had the family physicians taken a more active role, or had the families received periodic counselling by professional medical social workers is difficult to assess. However, one could speculate that the involvement of an informed third party would have, at least, deflected some amount of hostility which spouses often directed toward each other when their perspectives on the recovery clashed.

Reexamining the cases of Mr. Stein and Mr. Polski, we can see how their home care behavior may have contributed to a worsening of their conditions. These men could perceive no acceptable middle ground between full activity and invalidism. They opted to be as active as their pain would allow. In contrast, we saw that Mr. O'Shea and Mr. Grasso opted to accept a state of limited disability. While these men seemed to have a great deal less pain and other physical discomfort, their personal goals and aspirations underwent significant limitations. Both decided to change occupations to less arduous, but less rewarding ones. Moreover, this was not change mandated by the physician, but was in large measure influenced through a process of interaction with their spouses. The response to illness by Mr. O'Shea and Mr. Grasso was very different from that of Mr. Stein and Mr. Polski. Yet their management by Medical Group was highly similar. No one was referred for social service counselling, which is available to consumers of this prepaid group practice. I also think it is significant that each of the men were left to decide for himself when to schedule an appointment with the physician. While the needs of these men differed, their treatment by Medical Group was similar. This parallels what occurred at the outset, when the men sought help for their heart attacks. In each case, the medical system depended on the patient's initiated activity. During home care, the patient was again wholly responsible for deciding when and how to involve the medical care system.

We saw how patients and their families developed separate and dissimilar definitions of the situation during the hospital portion of the illness, which led to problems at home. This was shown to be related to the different access granted to patients and family members. The effect was for family members to perceive the heart attack and its consequences for future role adjustment of victims in a highly restrictive manner. They were more pessimistic about returning to normal activities than patients or staff members. Results of other studies indicate that this kind of attitude has wide prevalece in society. In a review of this literature, Monteiro points out:

> Although the medical literature on cardiac rehabilitation stresses the therapeutic nature of a resumption of normal activities by the recovering cardiac, the survey findings both in Louisiana and Indiana, as well as in Rhode Island, suggest that to the contrary the lay definition of cardiac illness protects the patient against the resumption of his normal role responsibilities, rather than encouraging him to leave the sick role.[5]

It seems that rather than altering such attitudes, contact with the medical care system can confirm them for the patient and his family.

As was pointed out in the previous chapters, structural differences between burwaucracies and primary groups make coordination of their activities difficult. We saw that when the patient was hospitalized, the medical care system was in control of the treatment, and the family was excluded. Once home, however, the control of the recovery process was left primarily to the family, with the result that the medical care system had minimal involvement in the home care decision making. This illustrates lack of coordination between the two systems. Yet when one examines the resources available to a medical care system such as the one which had responsibility for the care of the eight patients it can be argued that the problem was not lack of means for coordination as it was a failure to apply the resources. For example, Litwak and Meyer point out that bureaucratic organizations like hospitals have at their disposal professional persons (they call them "detached experts") who are able

> to actwith relative autonomy and by direct participation in external primary groups to bring group norms and values into harmony with those of the organization. They operate by becoming trusted (by the) members of the primary group the organization is trying to influence.[6]

Professionally trained social workers or visiting nurses come to mind as potential "detached experts". Medical Group had these available but no referrals were made which would have brought them into contact with the patients and families.

In my judgement, at various times during the hospitalization and at home, these families could have benefited from discussing their feelings and perspectives with a detached expert. Yet because only behavioral conformity was used as an indicator of adjustment to hospitalization, the nurses' assessments were that the patients were adjusting "normally" to the hospitalization. My data, however, indicate that patients were often confused and formed attitudes which inhibited smooth adjustment once they left the hospital. Moreover, family members were shown to lack an adequate understanding of the illness and its probable consequences. After hospital discharge, the differences between patient and family perspectives proved to be a major barrier to optimal family and patient adjustment.

During the home care, the behavior of family members, including the patients, was influenced by more than lack of information or confusion. To be sure, this existed. But the factors motivating behavior were ones which were rooted in strongly held sentiments and convictions. They were imbedded in the social and psychological bonds which made the families what they were. Under such circumstances, it was unlikely that brief meetings with the family physician which were held approximately once every three or four weeks would be adequate for the physician to even identify, much less address the problems families were having in managing the care at home. Perhaps, it could be argued that providing counseling to families would be very costly, especially when the present need is to reduce the cost of health care in this country. Yet the social cost of not providing the means to integrate the goals of rehabilitation with the realities of the family can be terribly high. Moreover, the mose effective means of reducing the cost of health care is by preventing illness and disability, and by reducing dependency on the health care system. Leaving people to cope alone after heart attack raises the risk of premature death, continuing morbidit prolonged disability (with or without medical cause), and deterioration of the family fabric.

The fact that the data in this report were generated from only eight families is a natural limitation of the study. Yet, because I was able to return to the homes frequently, and repeatedly speak with and observe family members, the findings have a high degree of authenticity. The patterns I reported were observed many times over in the homes in which they occurred. The members themselves were free to express what they thought was important about the issues they were coping with. I was also free to seek their help in clarifying events which I did not understand, or which seemed to contradict a tentative hypothesis of mine about family relationships. Although I cannot be certain about the extent to which the findings can be generalized to a large population of families, I am certain about the patterns observed in these eight families.

Since the data reported here represents what people repeatedly did, said, and felt, they are distinctly useful for studies employing large samples. These findings indicate what may be important variables affecting the outcome of illness like heart attack for any family. They may be of help in choosing the issues to examine and eliminate some of the risk inherent in selecting a limited number of questions to ask a large sample of respondents. In the time I spent with the families, I asked many questions and explored a variety of topics. I have abstracted out of many hours of interviewing and observing the key factors which influenced family behavior during the crisis. In so doing, I haveprovided clues and insights which may now be constructed into hypotheses for further study of families in crisis.

The typology I employed in this study was not so much selected beforehand - although the variables are repeatedly noted in the literature - as it emerged during the course of the study. My interviews and observations often centered about two fundamental areas of family life: services individuals provided for others in the family on a day-to-day basis; and the circumstances under which people sought out each other for sociability and emotional support on a daily basis, as well as situations leading to conflict. To facilitate comparison among the families, I thought it useful to conceptualize family behavior in rather broad terms. Role structure and companionship seemed to be reasonable choices to begin with. Once it became clear that within each family type, adaptive behavior during the home care was more similar than different in areas which had significant bearing on the recovery process, I decided to focus intensively on the association between the family types and coping behavior. Therefore, I did not attempt in this report to make distinctions within each type in terms of other aspects of family dynamics. Because of the similarities in coping tendencies within each family type and the differences between types, I also chose not to place the families on a continuum of role exchange, role differentiation, or role dissensus.

Using concepts such as role structure and companionship makes it relatively easy to test the findings of this study with a large sample. Moreover, these are important elements in all groups, not just families and one of the uses of this study is to suggest that the patterns I have described for families may be found to occur in other groups beset with crisis.

This study has demonstrated the feasibility of carrying out qualitative research in families at the time of crisis. Although the family members were burdened by fear, grief,confusion and emotional distress, they were willing, and sometimes eager, to share their thoughts and report their actions to a researcher. Critically ill patients on the Intensive Care Unit agreed to be interviewed, and in their delicate conditions would review for me the events that occurred during the day.

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DIAGRAM III - INDEX TO FAMILIES

A. Role Differentiated - High Companionship

Name	Goldberg	Grasso
# of children	2	2
living at home	0	1
Age		
husband	65	54
wife	64	53
child(ren) at home	xx	22
Occupation		
husband	housepainter (retired)	owner of gift shop
wife	housewife	inventory clerk
child(ren) at home	xxx	food outlet manager
Past Heart Disease		
husband	none	heart attach, 6 years ago
wife	none	none

B. Role Exchange - Low Companionship

Name	Asti	Polski	Stein	Warren
# of children	3	1	2	0
living at home	2	0	0	0
Age				
husband	60	64	58	66
wife	59	63	55	65
child(ren)	19(daughter) 21(son)	xx	xx	xx
Occupation				
husband	supervisor, dept. of highways	mechanic (retired) dept. of transportation	printer	mechanic(retired) dept. of transportation
wife				

DIAGRAM III - INDEX TO FAMILIES (cont.)

wife	housewife	housewife	customer rep. ins. co.	clerk/typist(ret
child(ren)	student construction laborer	X X	X X	X X
Past Heart Disease				
husband	none	coronary insuff.	none	none
wife	none	none	open heart surgery	none

C. Role Dissensus

Name	Ambrosio	O'Shea
# of children	2	4
living at home	0	1
Age		
husband	66	64
wife	65	62
child(ren) at home	xx	20
Occupation		
husband	fire department(ret.)	advertising displaysmain.
wife	school teacher (retired)	cook
child	xx	bank clerk
Past Heart Disease		
husband	none	rule-out heart attack
wife	none	none

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