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Sharing: the dying patient, his family, and those caring for him.

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SHARING
THE DYING PATIENT, HIS FAMILY, AND THOSE CARING FOR HIM



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SHARING
THE DYING PATIENT, HIS FAMILY, AND THOSE CARING FOR HIM

A Thesis
Presented to
the Faculty of the School of Medicine
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In Partial Fulfillment
of the Requirements for the Degree
Doctor of Medicine

by
Bruce Fabric
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of the requirements for the Degree of Doctor of Medicine.

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for

love, acceptance, belief

in my being and becoming

Albert Solnit

for

patience and tolerance--

thank you.

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Bruce Fabric, M.D.

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CHAPTER I

A REVIEW OF THE LITERATURE

Though death is normal (Guttentag, 1959), in all my years of medical school, I never once heard that statement. If man ascribes a goal and purpose to the ascent of life, then why not to death (Jung, 1959)? Growth and the unfolding of each individual is a process that does not end at the peak of man's ascent. At all times in a person's life, he is capable of growth. If man prepares decades for his ascent, then why not decades for his death (Jung, 1959)? Certainly such major religions of the world as Buddhism and Christianity have seen man's culmination at the moment of death. Even among the "more primitive religions" as practiced on the Solomon Islands, the burial is not the burial of a dead body but a transposition from toa (life) state to mate (after-life) state. This becomes a major event in the person's life, like pubescence or the founding of a family (Nagy, 1959).

Death in the United States is considered a "failure." In this country where man can banish pain with drugs and add over thirty-five years to his life span, millions do not so much as experience hunger--a daily threat to man not very long ago (Wahl, 1959). Since 1800 the life span of human beings has doubled in the United States as the result of understanding infectious diseases and their treatment, along with widespread application of preventive medicine and public health measures (Smillie and

Kilbourne, 1963). We live in an era where seemingly miraculous medical advances are expected and tempt man to prolong life at questionable cost. Recently the world and medical profession have followed with equal interest and awe both man's first heart transplant and man's first expeditions to the moon. A seemingly strong concept has developed that equates preservation of bodily functions with prolongation of life. Physicians have instruments at their disposal that can either assist or completely take over bodily functions for a patient. These machines can supply nourishment, assist in circulating blood, dispose of wastes, and deliver the required amount of oxygen to the body--a list by no means complete. Within the past few years there has also become available the services of a group that will freeze and preserve a body at the moment of death so that in future years this body may be brought back to life.

Thus, at present, a treatment race continues with each patient, and death occurs when the medical profession runs out of treatments (Kaufman, 1959). The moment is no longer a personal, intimate family affair. The patient is rushed to an emergency room of a hospital, where the family waits apart from him while the medical profession institutes dramatic measures of resuscitation (Ross, 1966). Much of this process results from a reductionist philosophy that regards the structures and function of a human body in only mechanical terms. While this has increased our knowledge of certain aspects of life, it has also led to our present day of reckoning (Aring, 1968). Simple biologic

continuance is the absolute good. Even in much of psychiatry today, man's psyche is explained only in organic terms. That which cannot be measured does not exist. I am reminded of an ancient ruler who, in trying to determine whether or not men had souls, performed an experiment. He weighed many persons, had them killed, and then weighed them again. Finding no difference in weight, he concluded that man has no soul. Our present medical path is a perversion of the Judeo-Christian value scheme. This value scheme has long emphasized man's freedom, integrity, and dignity. When these most valuable and precious aspects of man are gone, his mere biologic continuance is a violation of him as a person (Van Dusen, Clothier, Foster, Reeves, Goodrich, Beckman, & Wertenbaker, 1968).

If dying is normal, while the prevailing Western and especially American attitude considers death a failure, then what effects does this have on the mental health of individuals and the nation? Man cannot face life until he faces death (Pattison, 1969). Neuroses are related to the fear of dying, and especially suicides seem related to this fear (Jung, 1959). Man's adaptation to death is a necessary part of maturation and a deficiency in this adaptation is an integral factor in neurosis (Stern, 1968). Jung (1959) felt that in old age, not to focus upon death as a goal was as neurotic as in youth to repress fantasies that have to do with the future. A consistently observed experience in psychiatry is that a defense which enables man to persistently escape any fundamental external or internal reality is extremely costly in the use of an

individual's energy. The energy that becomes bound in this defense must be drawn from other sources. This leaves less energy to live in a free and creative way (Vahl, 1959). Perhaps this is why Jourard asks if man is committing suicide by going to a doctor. A doctor often increases the amount of energy placed in man's defense against the reality of death, thus draining energy from the tremendous need of human beings to live in a new, free, and creative way (Jourard, 1970). Solnit (McKegney, Isay, & Balsam, 1965) feels that we are now more ready to study the dying patient in order to cope with the reality that man is now capable of total destruction. Herzog feels that we are victimized with anxieties about conscious enemies. This anxiety is a secondary phenomenon that we experience because we cannot handle the primary individual confrontation with death. So this seemingly terrible death is seen as attacking man from without rather than existing within each man (Weisman, 1968). Coffin (Winter of 1968-1969) also feels that our fear of death is related to our national policy in South-east Asia:

"Death is an event embracing all our lives" wrote Berdyev, and how right he was. And the terrible thing about fearing death is that it results in fearing life, in a refusal to live freely, fully. If we think of death as the enemy, as something waiting to spring upon life as upon a prey in order to devour it, then death will exercise a terrible power over us. Either we take to living mouse-lives that are always waiting for the cat, death, to pounce, or we take to destroying others weaker than we in an effort to convince ourselves of our own power to survive. Or we can become so hypnotized by death as to be drawn to it as a moth to a flame, making death the very goal of life.

The problem of individual survival is not unrelated to the problem of national survival. How, for instance, are we Americans trying to secure ourselves against our

national insecurity? Well, we have upwards of four thousand nuclear warheads, enough to kill every citizen in the Soviet Union not once but thirty times over. And they have enough to kill us twenty times over. Who's winning? And according to a recent extensive survey of industry leaders in Dallas, Fort Worth, San Diego, and Los Angeles--the heartland of the military and aerospace world--our giant defense contractors are looking forward to bigger and better contracts to experiment with bigger and more wondrous weapons as soon as the war in Vietnam ends.

What can we say of a nation stockpiling over-kill, of a nation whose citizens sometimes seem more fascinated by devices to kill millions of people over thousands of miles than they are fearful of mass destruction, their own included?

And isn't it amazing that it never seems to occur to anyone that a corrupt, unjust, inhuman society is as much a lost cause as a nation occupied by a foreign power?

So to solve problems of national security we might do well to look again at human insecurity. We must stop trying to outwit death by cunning childish fantasies. As individuals, and as institutions and nations we must accept the fact that life is contingent, thank God, that death is not the enemy but simply a fact of life that must be deeply accepted as such. For what Christ is telling us in this parable of barnbuilder is that life can only begin to confirm itself when it consents to its end. Only when we stop trying desperately to secure ourselves against our insecurity, only when we give up self-protection for vulnerability can we begin to live, that is to devote our time, intelligence and strength to giving ourselves freely and joyfully to each other.

Those in the medical profession will never learn to help the anxieties of others if there is no attempt to understand and handle their own (Saunders, 1969). Kenniston (1968) found those who chose the medical profession to emphasize certain adaptive techniques or defenses. "There is an attempt to counter, master, and overcome sources of anxiety by active effort to change the environment, and highly developed ability to respond intellectually to troublesome feelings."

Some anxieties and troublesome feelings that the dying patient experiences are loneliness, loss of family and friends, loss of body,

loss of self-control, loss of identity, and regression (Pattison, 1969). Pain is also a major fear (Hinton, 1967). I would imagine fear of the unknown is also present.

I have already mentioned some of the hazards of too great a defense against such fears. What are some of the ways man has learned to constructively work with another human being and his fears? Much fear can be lessened by allowing a person to voice this fear (Saunders, 1969; Kubler-Ross, 1969). We, in the medical profession, need to learn how to be silent, listen, and just be there (Saunders, 1965). We must also become aware of what we are now doing instead of providing a real presence, i.e., focusing on technical interventions. Buber has written about being "with" another, being available rather than unavailable. This is similar to Marcel's "presence." This does not mean physical presence or availability, but rather the presence that allows another person to reach out when they desperately need to share a moment--whether of fear or joy--the availability of another person to share that moment, to really be with each other (LeFevre, 1966). Only when the patient is able to put his worst fears and thoughts outside himself is he able to engage in the very necessary process of helping himself to plan (Foster, 1965). Uncertainty is more difficult to deal with than truth (Horsley, 1969). The fact that the patient does not ask a question does not mean that he has none. It might mean that we need to listen better (Saunders, September 1965). When the doctor tells everyone the facts, the patient and family can prepare realistically for the future (Glaser and Strauss, 1965).

What can be done about the terrible fears of loss of self-control, loss of identity, and regression? We must be careful that in helping a person with such fears we do not do things to him instead of with him. Tillich writes that man cannot endure manipulation of having his "I-ness" destroyed. Man is broken if his resistance to being manipulated and objectified is broken. Medicine is an endeavor performed for human beings by human beings (Guttentag, 1959). These premises being true, it then follows that we must learn to care for the terminal patient in a way that helps him live as normally as possible until he dies. Plans must be made with him personally and his own individuality and dignity should be kept in the forefront of all thinking about him (Saunders, 1964). The patient should be allowed to participate in decisions, planning, and tasks. If the patient is approached as a person with the ultimate power of accepting or rejecting proposed care, then effectiveness of that care is increased and both the patient and staff satisfaction is increased. This is especially true in the nurse-patient relationship where goals can be set with mutual planning and consent (Skipper & Leonard, 1965). It is also helpful to emphasize the patient's rather than the family's right to decide how the patient wants to live with his disease (Quint, 1965). This type of terminal care, while helping a patient have his own death and his own dignity, can reduce much of the fear of loss of self-control, loss of identity, and of regression.

There are two quotes that emphasize this even more strongly and positively. The first is by LeShan and LeShan (1961) who

engaged in psychotherapy with dying patients:

In inexorable reality situations, the fear of death--and with it guilt and self-contempt--seems usually to be related to a sense of never having lived full in one's own way, of never having sung the unique song of one's own personality. Thus it is by the quest for one's own essence--by finding and engaging in one's own type of relationships and activities--that the fear of death may, perhaps, be most successfully eased.

The next is a poem by Holderlin (Kaufman, 1959):

A single summer grant me, great powers, and
A single autumn for fully ripened song
That, sated with the sweetness of my
Playing, my heart may more willingly die.
The soul that, living, did not attain its divine
Right cannot repose in the nether world.
But once what I am bent, what is
Holy, my poetry, is accomplished,
Be welcome then, stillness of the shadows' world!
I shall be satisfied though my lyre will not
Accompany me down there. Once I
Lived like the Gods, and more is not needed.

Cicely Saunders (1969) describes how to reduce and even remove the fear of physical pain, especially if there is a chronic pain that can become a disease in itself. She has found that by giving pain medication frequently enough, the pain does not recur, the patients' energies are freed from this worry and can be directed toward other interests and activities.

How do these ideas fit into our present system of hospital care of the terminally ill? Duff and Hollingshead in their study of the Yale-New Haven medical center (1968) mention some of the dilemmas involved. First, not all those persons involved--the patient, his family, all members of the staff caring for the patient--realized the illness was a fatal one. Sometimes members of this group were purposefully misled. This led to evasions, silences, half-truths, and deliberate lies that formed the

relationships and influenced the communications of one person with another.

A second dilemma arose from the fact that there are no explicit norms that can guide day-to-day relations of those involved with a dying patient and his family.

A third dilemma involved the uncertainty of when death would occur. Duff and Hollingshead found that long after death was imminent, the physicians continued to apply treatment measures to combat disease, suggesting in a manner that offered hope that the treatment might be effective. If one therapeutic treatment failed, an emphasis was placed on other alternatives. In spite of all this, the patient was aware of his condition in three out of four cases, but often did not share this with his physician or family because of the evasive form of communication. This served to isolate individuals from one another, the most alone person being the patient. Often the importance of treatment was highly overvalued while realistic concerns of the family and the dying patient were set aside and even ignored. At the time of death, the family seemed to experience a feeling of emptiness, while those who cared for the patient redirected their interest to other patients, cleaning the room for re-use, and obtaining a postmortem permit.

Another study found the doctor to be the authority on the when of death; the doctor did not communicate this too soon, knowing that he was the one who must face the consequences of an error. He would usually tell the nurse first, but might not tell anyone else. Often, he held back to keep the nurses and others involved

in the care working harder (Glaser & Strauss, 1965). Hospital personnel have been observed to be "cold" in terms of feelings. Often hospital routine takes precedence over dignity, respect, and humanity (Aring, 1968). Illness comes first in a hospital. Certainly patients do not come first. Every aspect of the patient's life in the hospital is directed and managed by someone else. Their place on the ward, the ward organization, meals, sleeping, and waking, as well as other activities concerning medical care, are not matters of the individual patient's choosing, but of the staff's (Barnes, 1961). Medical decisions often exclude both the patient and the family (Krant, Horowitz, Payne, & Sheldon, 1968). The greatest single cause of disturbance to the patient's peace of mind is failure of communication at all levels (Barnes, 1961). Communication is often denied the dying by all around them (Saunders, 1969). A patient's unwillingness to participate in this contrived way of relating often gives him the label of being uncooperative (Glaser & Strauss, 1965). The patient's ability to participate in planning, decisions, and tasks is not recognized. Excuses for patient non-involvement are "routine," "doctor's orders," or the "nursing shortage" (Skipper & Leonard, 1965). One study felt that much of this resulted from the staff's attempt to contain anxiety transmitted by patients about illness. A reliable system of defenses was established to contain this anxiety. Part of that defense, besides poor communication, was the division of patient care into a series of routine procedures divided between a number of different persons, all of whom were preoccupied with time and action (Barnes, 1961).

CHAPTER II

METHODOLOGY AND LIMITATIONS

This is an exploratory, descriptive study of phenomena associated with sharing and non-sharing within a medical care system composed of health care givers and health care receivers. This particular medical care system was involved with the dying patient. While the many limiting factors of this study prevent proving an hypothesis, I have tried to demonstrate what seemed to me to be interesting observations, associations, and speculations.

Glaser and Strauss (1966) give a strong defense of the value of qualitative research. They

contend that qualitative research--quite apart from its usefulness as a prelude to quantitative research--should be scrutinized for its usefulness as an end-product. To view qualitative research as merely preliminary to quantitative research neglects, hence underestimates, several important facts about qualitative analysis. First, it is more often than not the end product of research within a substantive area beyond which few, if any, researchers are motivated to move. Second, qualitative research is often the most "adequate" and "efficient" method of obtaining the type of information required and for contending with the difficulties of an empirical research situation. This applies particularly to the hospital setting with its very active developing situations. Third, sociologists (and informed laymen) manage often to profit quite well in their everyday work life from analyses based on qualitative research.

In doing my study, I have worked closely with a group of individuals doing another study. To avoid confusion, "study" applies to my study and "interdisciplinary study (IDS)" applies

to their study. The IDS is attempting to understand the experience and assess the needs and wants of the dying patient, his family, and those caring for him (Wald, Dobihal, Goldenberg, Wessel, October, 1969). The investigators of IDS include doctors, nurses, chaplains, and all other health professionals who are involved with the patients and families taking part in the study. They are collecting data over a two year period. The patients in the IDS have terminal illnesses, and seek help from Yale-New Haven Hospital, a large community teaching hospital. In the course of treatment, the patient and family may be seen in their home, in the clinic as an out-patient, on a hospital ward, or in a nursing home. It is important to note that every patient, his family, and the health professionals involved must choose to contract the services of the IDS. Studies of dying patients, their families, and those caring for them have been done before (Ross, 1969; Hinton, 1967; Duff and Hollingshead, 1968; Glaser and Strauss, 1965; Quint, 1965; Saunders, 1965; Pattison, 1969; McKegney, 1965; Solnit, 1959; Krang, 1968; Dobihal, 1969). However, while a study such as Dr. Ross' (1969) involved an occasional contact, the interdisciplinary study group is administering the ongoing care of the patient and his family over an extended period of time. This relationship provides for continual collection of data. The IDS has kept a diary of each patient, varying in length from three days to six months, and records reactions of the patient, family, and staff. There are presently eleven patient-family-staff histories which have been collected. The IDS feels that such continual collection of data is essential in attempting to

understand and perhaps modify behavior in an area so little understood.

The raw material is in two forms. Most is in the form of recorded perceptions of two nurses, Florence Wald and Kathy Klaus, who observe as they give an average of twelve hours per week of direct care to patients, work with families, and work with colleagues.¹ The nurse-observer writes brief notes, which she expands into detailed reconstructions within twenty-four hours. Transcribed tape recordings of conferences held between staff and others involved in the care of the patients are also available. For my study I selected patient number two from very early in the IDS Phase A, and patient number twenty-four, presently being cared for as part of IDS Phase C. The IDS phases are defined as follows:

Phase A: Pre-test of a nurse's study of dying patient; January 1, 1969 to July 1, 1969.

Phase B: Review of data, study of settings, revision of protocol to an interdisciplinary study; July 1, 1969 to October 1, 1970.

Phase C: Interdisciplinary study; October 1, 1970 and presently ongoing.

The method of participant observation can be criticized as being biased. While Taillie (1969) acknowledges that participant observation is more biased than non-participant observation, she points out that it has the advantage of giving the observer a certain "feel" of the situation, allowing concentration on those aspects of the situation believed to be most meaningful. In addition,

¹Krant (1969) views the nurse as the ideal individual to observe and record information of both physical and emotional states of the patient that he is likely to hide from his physician. The nurse is with the patient almost continuously, while the physician is with the patient intermittently.

the observer has access to his own thoughts, feelings, and perceptions as data that may be valuable in interpreting behavior. Keniston (1968) felt that to seek total objectivity when studying human behavior is pointless. He felt his own involvement was crucial and that his personal reactions constituted a major portion of the data. Glaser and Strauss (1966) contend that the fieldworker knows what he has studied and lived through, because not only has he been living and analyzing for months, but also he is participating in the setting in such a way that he can test his observations in daily experiences.

My study had access to all the data of the IDS. I did an exploratory study of two patients, their families, and those caring for them. Both of my patients have extended family ties in addition to the nuclear family ties of spouse and children. While generalizations cannot be made from two patients, what is learned can aid in looking at other patients. This can also be an important contribution to suggesting new or refined hypotheses. This limit to two patients also aided in achieving more depth and quality.

Initially, I read the raw data from IDS, attended IDS meetings, and met some of the patients. As I read the raw IDS data, I isolated four factors of information, feeling, decisions, and tasks. A very early discovery was that these factors never seemed to be isolated, but rather, each was associated with at least one other factor. I referred to these associated factors as clusters. Part of my initial analysis became an interesting game of uncovering clusters of factors; each cluster seemed to teach me something additional about the way these factors were associated.

I have isolated but four factors and how they are associated with sharing and non-sharing in a health system caring for a dying patient. Yet, I have demonstrated how these affect an experience which seems to defy being described by only factors. These factors are neither mutually exclusive nor jointly exhaustive in describing this experience. However, the factors will reflect some of the most significant interactions which appear repeatedly in the collected raw data.

After a review of the literature, I formed a philosophy of medicine that I felt was especially applicable when caring for the dying patient. This in itself was an extremely important process for me. It integrated my four years at medical school and my year at the Jung-Institute in Zurich, Switzerland. I felt that for the first time I had defined a system of medical care in which I would be willing to participate.

I then returned to over one thousand pages of raw data. Writing in an existential way, I considered each cluster of factors to be an experience that increased my understanding of how to implement a system of health care consistent with my philosophy of medicine. I called such a system a sharing system of health care. I examined phenomena associated with moving toward sharing. I also examined phenomena associated with moving away from sharing, i.e., non-sharing.

I defined a non-sharing system of health care, on the one hand, as one in which the four factors are isolated in specific roles of particular individuals. Members of this system, including patient, family, and health professionals, would behave isolated

one from another; each would gather his own information, keep his feelings to himself, make his own decisions, and carry out his own tasks. In addition, an individual might be fragmented so that, for example, his own feelings might be divorced from his own decision making. The tasks decided upon by one member of the system would be performed by another member with little or no access to information, feelings, or decision making.

The sharing system of health care, on the other hand, would regard these factors as functions not confined to a specific role. For example, persons other than the nurse could give personal care. Each factor could involve any or all members of this system, including patient, family, and health professionals. Many or all members of this system would gather information. Feelings of members of this group would be shared. After considering the information and feelings, many or all members of this group would share in the decision making. Then many or all members of the system would jointly perform the decided upon tasks.

In summary, persons die; persons grieve; health professionals attempt to help. Much of this help in the past has focused on maintenance of bodily functions of the dying. Recently attention has been refocused on helping the person as he experiences dying. Part of the goal of this study is clarification of phenomena existing around sharing and non-sharing systems of health care in the context of the experience of the individuals involved. Specifically evaluated are phenomena associated with sharing and non-sharing of information, feelings, decisions, and tasks. Are such phenomena seemingly detrimental or beneficial, and to whom? Do members behave as if

guidelines (explicit or implicit) exist which determine sharing or non-sharing? What seems to foster or hinder sharing? Hopefully, this will aid others in an approach to the day-to-day experiences of working with the dying.

CHAPTER III

PROLOGUE TO THE FINDINGS

This paper is written in a chronological order. The findings do not constitute complete case studies, but rather, I have used material from these two cases to show a natural development of a sharing system of health care. Because this system develops slowly and is only clear by the end of the paper, I have written this prologue to orient the reader to the findings of the paper. These findings will not be substantiated here, but in the text of the paper. I wish to emphasize that many of these findings are in the form of interesting speculations.

(1) Health professionals are oriented toward doing technical intervention to affect bodily illness in a dying patient. While this may meet bodily needs, it often runs counter to the patient and family's felt needs to experience a certain quality of life. Health professionals, especially doctors, tend to cope with "bad" feelings, such as anxiety, by forming and using intellectual concepts that aid in doing technical interventions. While this may be health professionals' way of coping, this may not be the best way for patient and family to cope with these feelings.

In the system of health care studied, the nurse-observer consciously sought feelings and needs of patient and family.

She then either expressed these herself or encouraged the patient and family members to express them. Initially, the other health professionals involved with the care of these patients did not know how to integrate this increased sharing of the patient and family's needs and feelings. Some even blamed the nurse-observer as the source of this turmoil and labeled her a trouble-maker. Yet, it became clear that the more information that was gathered around the patient's feelings, the better his needs could be met. If the patient's and family members' expectations of having their needs met were greater than the health professionals' ability to meet their needs, this lead to agitation and frustration for all those involved. An example of an early attempt by health professionals to integrate some of the family's feelings and needs was by working with only those family members that agreed with health professionals' decisions.

(2) There were various blocks to sharing among patient, family, and health professionals. Common among health professionals was the fear that a real confrontation with the patient on a feeling level might destroy the health professional-patient relationship. Some blocks to communication included language barriers, role boundaries, feeling tolerance of a listener, limitation of resources, and need for the dying patient and family members to separate from each other. There were examples of patient, family members, and health workers feeling frustrated, angry, and powerless when they were excluded from sharing information and decision making. When there was a

separation of decision making by one person and task performance by another this did not always best meet the patient's needs and wants. When decisions were made by certain health professionals and not communicated to the others involved in the patient's care, this also led to anxiety and anger. The patient, family members, and health professionals experienced as negative many of the phenomena associated with these blocks to sharing. On the other hand, total sharing of information without regard for feelings was also experienced as negative.

(3) A strong block to sharing was the non-acceptance of death. This is seen most strikingly in the oldest son of both families, leading to decreased contact between the non-accepting individual and the rest of the family, including the patient. The non-accepting individual also had an increased contact with health professionals in a task-oriented, treatment-alternative search. This person was the most upset by apparent mistakes or mishaps of treatment and sought for someone to blame for the patient's death. Each of these oldest sons exercised power in decision making not held before the parent's illness. Each felt personally responsible for decisions and attempted to spare other family members by keeping them uninformed of information, feelings, decisions, and tasks.

Non-acceptance of death by the patient also led to non-sharing in an attempt to spare family members from bad feelings. Non-acceptance of death by health professionals also led to non-sharing and task-orientation.

When one person, whether patient, family member, or health

professional, did not share (in an attempt to spare the others), such behavior often led to the felt needs of family and patient not being met.

(4) Feelings seemed to have the most influence on medical decisions, in spite of medicine's strong association with science and intellect. Yet, while there was an explicit way for people to examine openly the intellectual aspect of decision making, there was at first no similar way to examine openly the feeling aspect of decision making. This developed later, however, with the natural development of a sharing system of health care.

(5) Guilt was the strongest feeling to affect medical decisions. I have pointed to how those not accepting death seemed least able to tolerate this feeling, and sought for treatment alternatives, attempting to fix blame for the patient's death. Such an individual also isolated himself from patient and other family members, thus blocking sharing. As the system moved toward sharing, there was less searching for blame and a greater tolerance of guilt. A sharing system moved away from fixing legal blame for bodily injury and moved toward guilt for injury to patient and family's feelings. I did not consider this guilt as bad, but rather as a natural phenomenon experienced by all members of a system caring for a dying patient, and best handled by open sharing.

(6) A sharing system of health care regards patient, family, and health professionals as all being capable of sharing information, feelings, decisions, and tasks. With many members involved, there at times developed differences in feelings and

opinions. If these differences were to be resolved, dialogue was needed between members. Still, not all differences could be resolved by dialogue. It then became necessary to establish priorities as to whose feelings and opinions would be regarded as most important in forming decisions.

(7) This sharing system raised many questions about traditional doctor-patient relationships. Who should decide what information should be shared? Whose feelings were most important? Who makes medical decisions? Who performs health care tasks? The search for answers to these questions involved many painful experiences. Health professionals experienced as painful the open integration of feelings into medical decisions. Major decisions often took on a crisis nature. Health professionals gradually allowed patient and family members to be more active in decision making, but there were setbacks to sharing when the exasperated health professionals felt that only a doctor, not the family or patient, should make medical decisions. At other times the health professionals showed tremendous strength in tolerating feelings, offering unlimited time, and sharing decision-making power with patient and family.

(8) A workable model of a sharing system of health care was eventually reached when the system was described as a team. The patient was the captain, the health professionals acted as coaches, and family were members of the team. The patient as captain decided upon the limits of sharing and non-sharing. He indicated how much information was to be shared or not shared, to what depth feelings could be shared or not shared, and how

independent he wanted to be in making decisions and performing tasks. In this system, non-sharing then was equally important. This evolved from placing the patient's feelings first, the family's second, and health professionals' last. What was most important to be shared was not merely information or feelings, but power, usually held by health professionals and at times usurped by family members, to decide the limits of sharing. The health professionals allowed this team model to work as long as no undue pain was being afflicted on family members.

(9) The patient decided the goals of this team, often, but not always, choosing quality of life as more important than quantity of life. The hospital setting often had a negative effect on the quality of the patient and family's experience by isolating the patient, not allowing him to share and be active in his own care, and thus offering him invitations toward infantilization. When allowed to be more active in sharing information, decisions, and tasks, the patient and family's quality of experience was often affected in a positive way. The sharing system of health care regarded the patient as a mature individual capable of making significant decisions, potentially able to grow, and capable of giving as well as receiving. When the patient felt he was not capable of making a decision, he was allowed to designate whom he wanted to decide for him.

In giving the patient's needs and feelings such priority, other members of the system at times went to the extreme of

failing to meet their own needs. At one point, such a member was reminded that he would have to be "captain" of his own life. Even though members of this system attempted to let the patient shape his destiny, these members still had to shape their own lives to the point that the patient did not deplete all their energy.

(10) Health professionals who helped to increase the quality of the dying experience for the patient and family also experienced an increased quality of this experience.

Such health professionals asked themselves if they had done everything they could as people (not merely as health professionals). They also shared intense moments with family members and patients in which they felt really "with" each other, really "available," truly "present."

CHAPTER IV
THE FINDINGS

The first person I will describe was the second patient in the IDS study, and was cared for during the pre-test phase of the IDS. The notes from this phase are not always detailed or complete, but I have worked with the information available. Mrs. Wald's notes and the tape-recorded sessions are like a flash-light in what seemed to me a very dark and depressing enclosure. As more and more of this enclosure became familiar to me, I became convinced that there was no need for the darkness and depression.

Mr. X lived most of his life in Italy. Born there in 1908, he was a robust man, a family man, a hard worker. His life seemed simple, yet full. True, he had a heart condition as a child, but that had never weakened him nor kept him from going to work early in the morning and returning near the end of the day. At home in this country, he was devoted to his very close and, at times, very heated family. His wife rejoiced in cooking and cleaning. She, like other members of the family, knew that Papa was the absolute head of the house. In return for this total respect from his family, he was a benign tyrant filled with love. So each day was work, home, food, family. Anthony, the oldest son, had academic problems early in his

schooling, and was sent to a boarding school. This, coupled with his being the first to come to America, learn English, and successfully set up his own business, set him somewhat apart from what was otherwise a very close and traditional Italian family. One by one, eight members of the X family arrived in this country. Only two stayed behind. As they arrived, the family members re-established the close-knit family life pattern of Italy. Mr. X arrived in the early 1960's, and again was the patriarch of the family. He worked for over eight years as a heavy rock and construction worker. From the mid-1960's on, his heart weakened to the extent that he required medication daily, but he still worked steadily. He was under the care of a local family practitioner of Italian background. In August of 1968, the patient began to experience pain in the lower right abdomen. At the suggestion of his son, he came under the care of a suburban M.D. whose field was internal medicine. Repeated hospitalizations in a local hospital (Norwalk) and multiple tests offered no better understanding of what was happening. Because of the persistence of this pain, the patient was admitted to Yale-New Haven Hospital for further evaluation. On November 29, 1968, x-rays taken of the large bowel after an enema was given with barium showed no abnormalities. Yet the following morning, the patient had, on examination, evidence of some acute process occurring within his abdomen. He was immediately taken to surgery where the surgeon opened the abdomen and discovered that a catastrophe had indeed occurred. The blood vessels that nourish the intestine had been blocked

and the intestine had died from the level of the third duodenum to the proximal transverse colon. If nothing were done, the surgeon perceived that the patient would die shortly after the operation. The surgeon removed the dying portion of the intestine, hoping that, over time, the eight inches of bowel left would compensate by increasing its ability to digest food. Only this would allow the patient to digest enough food to prevent a slow death from malnutrition. It is interesting to note that two months later when the nurse-observer interviewed the surgeon, he still wondered whether or not he had made the right decision.

With so little bowel, food passed through Mr. X very quickly, so that he had continual diarrhea. If the fluid in the diarrhea was greater than the fluid he was receiving he would become dehydrated. Also, when Mr. X had diarrhea he lost certain salts from his body. If these salts were not replaced, he ran the danger of becoming weak or having a cardiac abnormality and dying sooner. To supplement food, water, and salt intake an I.V. was attached to his body, which ran four twenty-four hours a day. Even with this supplementation, it was very difficult to maintain his fluids and salts in the range compatible with life; and he still did not receive enough food to prevent his dying from malnutrition.

From November 29 until January 2 the patient was sustained on intravenous fluids. For a man whose greatest pleasure was eating his wife's well-seasoned peasant type southern Italian cooking, this changed must have had a marked impact. On January 2, 1969 he was transferred to the clinical research center of

the hospital, so that his ability to discontinue intravenous fluids and attempt to resume oral food intake could be assessed.

On February 6, 1969 the patient came under the care of the IDS. Before initiating direct care for Mr. X, the nurse-observer met with the social worker involved with this family. The social worker felt that it was hard for anyone to accept death. Factors that influenced her acceptance were her culture, her own reactions to death, her relationship with the patient, and her ability to really do something with the family or the patient. Because the patient spoke almost entirely Italian, the social worker did not work with him directly. She chose to work with Anthony, the oldest son. When the social worker asked Anthony to come to her office, her reason was to make arrangements for the discharge or transfer of the patient.

(Author's comment: To overcome a barrier in sharing information, the social worker chose to work with an English-speaking member of the family. This also seemed necessary to meet her stated needs of establishing a relationship and doing something for the patient and family. While this met her needs, I am not sure the patient's needs to share information were also being met.)

During the interview, Anthony appeared anxious and depressed. He sat down and said immediately, "I'm a big boy. When is he (Mr. X) going to die?" The doctor and social worker insisted that this was impossible to determine. The social worker and doctor wanted to investigate how adequately the patient's wife might care for the patient, what facilities

were available in his home town, and the possibility of sending him back to the hospital in his home town. Anthony remembered the numerous admissions and tests at that hospital where nothing was actually done for his father. Anthony was very upset and wanted his father to stay at Yale-New Haven Hospital where he was getting good care. He asked the doctor why he would send his father back to a hospital where they didn't do anything for his father. Apparently this evoked guilt feelings in the doctor and social worker.

When the social worker and the nurse-observer met, the social worker asked how much more can the staff do for the patient or his family? She said, "I mean how much more medically can you do for him?" The social worker stated that the patient required I.V.'s to sustain his life, since every time the staff had taken him off the I.V.'s he had gotten into difficulties. Because there are no agencies in any community that would come into a patient's home and place an I.V. in his arm, he might have to go back and forth to the hospital during the day, and be home at night. The social worker did not know if the patient or family could tolerate this. The social worker felt that the only reasonable solution was for the patient to be transferred to one of the state chronic disease hospitals.

(Author's comment: Here was the dilemma. The social worker understood that the hospital could not do anything for this patient. Anthony was angry that the staff would send his father away from the hospital that had done things to keep his father alive and back to a hospital that did not do things

for his father. The hospital bed was a "research bed," meaning it could only be occupied by a patient upon whom particular medical research could be done. The staff felt guilty. The patient was upset and impatient that he could not do what the staff expected of him.

This is a good example of how medicine, in our society, functions as a coping mechanism for bad feelings such as anxiety. When bad feelings arise, everyone tries to do things. If nothing can be done, the anxiety remains. To rid themselves of this anxiety, the staff send the patient somewhere else.)

Anthony, at the conference with the social worker, claimed that he had saved his mother by not telling her anything of what was really going on. Anthony did not feel the time was right for this. He described his family to the staff as incapable of understanding. He felt that he was the oldest son and should carry the burden of responsibility. He also said that he kept a stoic attitude when he visited his father, so his father did not realize that Anthony was worried or concerned.

(Author's comment: Anthony, who had been called in to share information, planning, and decision making, was the largest obstacle to sharing between patient, family, and staff. He attempted to contain all the bad feelings within himself. This is a self-assigned role that often seems to be taken by the oldest child. In order to avoid contaminating others with these bad feelings, he will spare them by remaining isolated from the rest of the family and the patient. This type of role usually usurps the power and decision making structure

in a family. There is the added benefit of intrigue of meeting secretly with staff members to plot the next strategy. The burden that goes with this role is the feeling of entire responsibility for plans and for anything bad that happens. This role tends to maintain all the guilt in one person. One thing seems obvious: a family can hardly make realistic plans without open discussion and understanding of all available information.)

The doctor, a research fellow in charge of the patient from January to February 15, spent much time listening to and trying to answer questions from other members of the family when he met them on the ward. He also made himself available evenings, weekends, etc. No matter how much time he spent going over the questions, the staff felt the family members did not hear the answers. The social worker interpreted their response as a type of protection for them: they heard only what they wanted to hear. The patient himself had been getting thinner and weaker. The social worker felt that he must know what was happening to him, but no one at this point had verbalized that he would be dying, perhaps over a long period of time. Only one doctor on the staff spoke Italian well enough to sit down with the patient and let him know his condition from a medical stand-point. However, this was done shortly after the surgical procedure, at a time that the patient probably could not comprehend conversation. The research fellow felt the patient knew that his digestive system was not alright, and that his existence depended upon the bottle and I.V. going into his arm.

(Author's comment: One block to communication might be not speaking the same language, whether Italian or complex medical terminology, but another block to communication is a limited tolerance feeling-wise of the listener--in this case, the family--to hear the information. Where feelings block information, questions may have to be answered patiently over and over. On the other hand, the feelings might be dealt with directly.)

Initially, the nurse-observer felt that the only person in the family who could put things together intellectually was Anthony. She felt that Anthony was isolated and decided to support him as a way to mobilize the family. At that point, all she communicated with other family members was by gestures, facial expressions, and acts such as sharing a cup of coffee. Mrs. Wald saw part of her task as encouraging Anthony to communicate more openly with his father so that the two of them could better cope with the situation. She also wanted to involve the patient's wife in the process because of the wife's non-verbal behavior which indicated involvement (holding his hand, trying to feed him, refusing to leave his side). The nurse was trying to discern at what point the family was ready to be involved with the patient care, including the dying process. When the family was ready to be involved, she felt another person could help them move. The nurse-observer also felt that Mrs. X could start learning English, but the fact that she had not learned English in the nine years she was in this country did not make this seem likely. During the

period when the patient was comatose, the nurse-observer encouraged the mother and son to share sitting with the patient and seeing to each other's needs for rest, food, etc.

(Author's comment: The nurse-observer was trying to change the intra-family communication system from one in which Anthony blocked information to one in which he would feel support enough to share information. Hopefully, this would lead to sharing feelings, decisions, and tasks with the other members of the family, the patient, and the staff. The language barrier accentuated here what happens to many patients even without a language barrier.)

On the ward, the nurses were irritated because they felt the family blamed them for the patient's condition. The nurses felt this was unrealistic and the family was not taking into account how seriously ill the patient had been when he arrived on the ward. The nurses felt the family was angry and also felt there were too many staff members involved in the care of Mr. X. Most of the family tried to keep out the doctors, especially those taking blood. Anthony was the least interfering; the wife was the most interfering.

(Author's comment: Blame and guilt are important feelings to follow. In much of the data this feeling seemed to be the most powerful motivation behind decisions and the set-up of different systems. Here the nurses have decided to stay away from a family that seemed to be blaming them. I am not saying that this is right or wrong, but that it is happening.)

At this point came a very important decision being considered by the staff--the decision that the treatment of this person was changing into the care of the dying. This had a very important influence on whether to allow the patient to return home or not. First, I would like to quote a beautiful expression of this moment by Cicely Saunders (1966):

One of the most important decisions comes, of course, at the moment when you decide that your treatment of an individual is changing into the care of the dying. Now, this may not be a particularly definite moment, the care may go on the whole time in the same unit with the same group of workers. But there is a moment--there is a time to live and time to die, and there is a difference between prolonging living and prolonging dying, and I think we have to learn to try and recognize this. The fact that it is possible to do some particular kind of treatment doesn't necessarily mean that it is either right or kind to do it, and there is a path between too much and too little activity and treatment and there is a place where the aim of what you're doing and the criterion of success finally changes. Sir William Osler is quoted as having said, "I have gone too far across the river to want to come back and have it all over again." . . . To recognize it is not defeatism on the part of either the patient or the doctor, but rather respect and awareness of an individual person and his needs. Jung talks about the preparation for dying which begins first of all in the subconscious, and goes on to say that the subconscious makes surprisingly little ado about the fact of death, being concerned how it is achieved.

Decision to send the patient home

The doctor caring for Mr. X stated that it was most difficult to decide what to do for this patient. When there was a feeling of hope for long-term survival only two weeks before, a decision had been made to be very aggressive in getting the patient off his I.V.'s and back to food by mouth. But then there was an increasing realization that this goal could not

be achieved; vomiting, electrolyte imbalance, diarrhea, and weight loss were occurring. The doctor felt he was taking his cues from the family when he decided that it would be better not to unnecessarily prolong the patient's survival. After this decision the patient experienced another acute episode, becoming obtunded. As he began recovering, the family was very happy. The doctor then wondered what the family really wanted, and said he hated to think he was taking his cues from the family. As long as the family would like to see the patient survive as long as possible, he would like to be aggressive in treatment. On the other hand, when the doctor saw how much havoc this was causing the family, his inclination was to be less aggressive in treatment; he would do everything possible to make the patient comfortable and support him within reason, but would not do anything heroic to prolong that time.

(Author's comment: The viewpoint being expressed is the doctor's. What becomes more and more clear is the extraordinary influence of feelings. This is extraordinary to me because nowhere in my medical school was the importance of feelings emphasized in making decisions.)

Information that the patient was capable of remission and could be freed from external apparatus such as the I.V. was associated with hope and aggressive treatment. Information that the patient could not become independent of this apparatus was associated with loss of hope and less aggressive treatment. But what is equally important to notice is that hope

and loss of hope are feelings within the doctor treating this patient. These are not necessarily the feelings of the family or patient. While life and its extension are still the goals in this system, the doctor's feelings are considered most important. And the doctor's feelings have the strongest influence in affecting decisions and tasks. On the other hand, when the prospect of dying arrived, the doctor then allowed the family's feelings to be most important. According to him, he first took cues from the family to be less aggressive, then more aggressive, then again, when he noticed havoc in the family, less aggressive. Later in the study, the nurse learned how little confidence the wife had in modern medicine; the wife fought to have her husband home. Looking at feelings is one way to find continuity in what happened. Nowhere do we hear what the patient's feelings were, except by inference. The nurses felt his coma was psychological, not physiological. Nowhere do we hear an explicit method of determining the patient's and family's feelings. Nowhere is there a way for a dialogue to exist where these factors can be shared with all members of the system. When it comes to the family's or patient's feelings, the staff often functioned on their own perceptions of what the family felt, or on remarks overhead perhaps days before, or on complete ignorance.

All parts of a system are always present, but only certain parts of a system are consciously used. Of those parts that are brought out in the open, some are given a higher priority of importance in influencing decisions.

The doctor felt that the next decision of whether or not to send the patient home was very difficult. He was convinced that to send the patient home would seriously shorten his life. The staff's crude assessment of the family's feelings was that the family would be happier to have the patient home for a short time than to have him in the hospital for a long time. The family also felt that the patient was invincible; to the family the patient surmounted one crisis after another and the family each time refused to believe that another crisis would come along. The nurse-observer was not certain that the family understood the consequences of taking the patient home. The doctor told Anthony, the oldest son, that this would shorten his father's life--that his father would get in trouble more quickly at home than at the hospital. The head nurse was not sure the family understood this. The doctor agreed that the family listened only to what they wanted to hear. Anthony saw only that his father bounced back and the staff was not really doing a lot for his father except changing I.V. bottles, and that could be done at home. Another reason the family believed the father was invincible was that he no longer needed medication for his failing heart. The patient had lost so much weight that his heart did not need to work as hard. However, the patient still had severe heart disease. The family, seeing that he no longer needed the medication, believed he had overcome one more hurdle. The doctor admitted that even he felt the whole case had been one ambiguity after another.

The nurse-observer wondered about the ability of the family

to withstand guilt for doing something on their own, such as taking the patient home. The previous week, when the patient became more ill, Anthony, his brother Albert, and his mother got into a fight, blaming one another, and Anthony had suffered great guilt. The head nurse said that an evening nurse had overheard a spat between Anthony and his mother in which the mother had said to Anthony, "What did you make him go to the hospital for? If you left him home, he would have been all right." The head nurse felt this showed that the mother was in complete ignorance of what was done and why. The nurse-observer felt that where massive intervention is employed when a patient is terminal, guilt is common. If this is true, does one intervene? The doctor also felt Anthony was under fantastic pressure, and that everyone could tolerate taking the patient home except Anthony, because no one else had enough understanding to realize the consequences. The doctor talked to Anthony about the pressure and asked if he would feel comfortable with the consequences of taking his father home, i.e., a shorter life for his father. At that time his father was deep in a crisis and Anthony decided his father should remain in the hospital. But a few days later, when his father was well again, Anthony was anxious to have his father come home.

The nurse-observer felt that in the goodness of the family's heart, they saw the staff had not cured Mr. X and they wanted to try themselves. The staff's expectations were that this would not work, but if the family found this out at home alone, they might become panic-stricken. This would be hard on both the

family and Mr. X. The nurse-observer suggested that the family be allowed to take more and more responsibility for the patient's care in the hospital; for example, that Mrs. X suggest the diet and feed her husband. Then Mrs. X would see the consequences while the staff could still be there to give her support. The head nurse felt the family would blame the staff's medical management for any bad results. The nurse-observer felt if the patient died in the hospital, the family would blame the staff, and if the patient went home and died, the family would also blame the staff because the staff said the patient could go home.

On the ward, the patient heard the staff doctors outside his door and asked his son Albert what they were discussing. Albert related to his father how the doctors were considering sending him to another hospital in his home town where he would remain on I.V.'s for a few more weeks. Albert told the doctor how his father felt about that. The patient said he would rather go home and die than spend the rest of his life on an I.V. He also said if he had access to something he could take, he would kill himself. Albert indicated that his mother was also under tremendous strain.

Before hearing this, the doctor said he felt comfortable that the staff was providing Mr. X a very comfortable existence, and that at least he was not in pain. The only thing the patient had was an I.V. Now the doctor realized that this was really a very uncomfortable, miserable life in being so different from what Mr. X wanted for himself. The doctor felt

confused as to what was more desirable. He felt probably the best for Mr. X and the others was for Mr. X to have one week at home, get progressively into more trouble, and then have something come along and end the misery of the whole family. The doctor felt that one week of progressive downhill deterioration at home was more desirable for the patient and his family than two months of stability in a hospital. The doctor stated that if the patient died in the hospital, Anthony, rather than living with guilt, would live with his mother, who would hate him for the rest of her life, accusing him for the responsibility of his father's death. Mrs. X would be convinced the patient died because he stayed in the hospital. Anthony would be happy knowing he did not kill his father by sending him home. On the other hand, if the patient went home, the only person that would suffer was Anthony. The mother would be happy and the patient would be happy.

The head nurse did not believe this family realized they were killing their father by taking him home. The doctor said the family was killing him a little bit earlier than he would die naturally. The head nurse again raised the question of blame. The doctor said he didn't really care where the blame was fixed because he knew the staff had all worked so hard. The head nurse wondered what would happen if the language barrier was not there. She asked, "Have we given the patient a choice?" She pointed out that the family had always looked up to the father as a patriarchal leader. The head nurse asked how the patient would feel if the staff had said,

"We know that you want to go home, but you'll be dead in a week. If you stay in the hospital, you'll be alive, walking around." The doctor did not think the patient should make such a choice, although he recognized that he was letting one of the sons and Mrs. X make that decision for him. The doctor said he was denying the patient that choice because he found that going too far. The nurse-observer suggested an interpreter could be used to ask the patient how he felt and what he would like next. The interpreter would not have to tell the patient he was going to die, but could ask such questions as "Do you know what this might mean if you go home?" The nurse-observer also felt this should be done in the presence of the doctor, who had good rapport with the patient. The doctor agreed to this and wanted to do it as soon as possible.

Through the interpreter, it was explained to both Mr. and Mrs. X by the doctor and the nurse-observer that the chances of living longer at home were much more limited. The doctor gave a comparison of two months at home or two years in the hospital. The interpreter stated that both the patient and his wife unequivocally wanted Mr. X home, and both agreed that "things were in the hands of God." Mr. X said that he wanted to go home and die there. He didn't care how long he had to live, but he did want to be at home. Having determined this to be what the patient and his wife wanted, the nurse-observer moved quickly to carry this out.

Before the final decision was made, the nurse-observer asked Anthony to call the whole family together in the patient's

home so that she could explain what might be expected and what the family would need to do in order to care for the patient at home. She also explained that a visiting nurse was available and that she would be in the home three hours a day to help, but that the private physician did not think the family could manage the I.V.'s and therefore private nurses were needed.

The family appeared to understand and want to participate. Mrs. X proudly showed how she was arranging the den as a bedroom so that Mr. X did not need to climb stairs or be isolated from the mainstream of life. She shyly asked if she should sleep with her husband? The nurse-observer responded that this was something she and her husband could answer better. On leaving the house, Anthony shared with the nurse-observer his feelings that the family did not really understand and would not carry out their responsibilities. This surprised the nurse-observer because she felt they understood and seemed honest and hard working.

(Author's comment: There has been a movement in this system toward more sharing of information, feelings, decisions, and tasks. The physician in charge felt comfortable until the feelings of the patient were relayed back to the physician. The patient wanted to die rather than continue treatment, and if he had access to something that would kill him, he would have taken it. The real needs of this patient ran contrary to the treatment which offered him the longest time to live. The feeling of guilt appeared. Medicine today seems to be a

system in which the type of treatment done is that which is offered and expected in most places. If this is not done, the threat or fear of legal prosecution is in the background. A legal view searches for blame. This seems to be one of medicine's latest infections--legal blame. Most treatment approaches which are routine or carried out in the properly equipped institution escape legal vulnerability. Once a patient becomes involved with a medical system that has advanced and complicated treatment modalities, it is perhaps harder not to be treated, or to have treatment halted at some point, than to be treated maximally. The person who decides not to treat, or to halt treatments, is looked upon accusingly by others, and is charged with the blame for "killing."

This blame seems to be a perversion of the natural guilt felt by all or many of those involved in a system where a person is dying or has died. If a system respected each of its members, especially the dying individual, as being responsible and capable of making decisions, then blame would not have to be fixed upon any person. Instead, persons could realize and accept guilt as a natural phenomenon around death that everyone feels to some extent. Also, if medical care were a human right and not a fee-for-service privilege, this would remove another large incentive for affixing blame, i.e., an attempt to legally fix blame on a person or institution in order to reduce or eliminate the charge for health services.)

The next aspect of the decision to send the patient home was the technical question of how long and with what equipment?

Again, I would like to stress the non-technical aspects of this part of the decision.

The doctor felt the patient should have a new I.V. placed directly into one of his veins shortly before he left the hospital. This would allow the patient to receive the necessary salts and fluids to keep his body in balance. Without such an apparatus in the past the patient became dehydrated, his blood pressure fell to a low level, and he looked very poor. The doctor and head nurse were concerned that as soon as the patient was home, the family would over-feed him. Since the patient had such a small amount of bowel left to handle this overload, the patient might have even more diarrhea and become increasingly dehydrated and malnourished. The nurse-observer felt that the health professionals should let the patient and family take the lead. If they fed him and he got diarrhea, that was acceptable. The health professionals could support the family, saying the patient would not have lived anyway and that he got a lot of pleasure from home. The nurse-observer also wanted to know whether, if the I.V. did not function properly and had to be removed, the patient could wait until his private physician came around the next day on his house call. She felt that way this would not terrify the family if the I.V. discontinued for a short period. This was agreed upon.

Then came the determination of how long the patient could stay home. The head nurse suggested he could go home on a twenty-four hour pass. The nurse-observer and the doctor felt

this to be a good idea. The head nurse said that if they felt they could manage after twenty-four hours, this was up to the family. She also said that the staff members realized they could not prolong this patient's life forever. She said, "Just want to give him a chance to be home and have mama care for him a bit. If this doesn't work in the first twenty-four hours, she'll be a heck of a lot happier about the support she's gonna get when he comes back in." Some of the health professionals' emotional reactions to the family's dissatisfaction with the patient's hospital care came out in the following comments: The doctor said that the family would quickly realize how difficult keeping the patient at home was: "Let's see how the family copes with the patient urinating in bed." The head nurse added quickly, "Right, and stooling in bed! You're right! Let them have it full blast!" The doctor said, "Unfortunately the patient would not get into that much trouble in twenty-four hours. Even if we pulled out his I.V. and fed him, he would not deteriorate." The head nurse added, "Anthony claims to know so much about I.V. bottles. Let him see how much just moving him around can work on an I.V." The health professionals decided to make it even easier for the family by preparing the I.V. mix to take home, giving Mrs. X practice in the hospital with the I.V. and measuring out the dose for oral feedings. This would allow the patient to return to the same hospital ward if out only on a pass. The translator met with the health professionals, the patient, and the family. The family understood the difficulty of taking their father home and still wanted to do so. However, the

patient and his wife objected strenuously to having to return to the hospital after only one day and wanted Mr. X to stay home indefinitely. This, then, was the final decision: the patient would go home indefinitely (for discharge summary, see Appendix I).

(Author's comment: A decision was being made for quality of life rather than quantity of life. Quality is much more related to feelings than quantity. The health professionals planned several ways to reduce the bad feelings of fear and guilt. They would allow the family freedom of choice in meals and the family would be given the message not to fear the I.V. malfunctioning. Part of the decision seemed to be influenced by anger on the part of some of the health professionals, directed toward the family because of their lack of appreciation of the patient's hospital care. Some of the health professionals seemed to want to teach the family a lesson, hoping that when the family returned to the hospital with the patient, they would be much more appreciative of the hospital care given the patient. In the end the patient's and family's feelings predominated in deciding not only to take the patient home, but also to keep him there indefinitely. In the hospital, the family would receive preparatory training that would enable them to perform many of the patient-care tasks at home.)

Moving into the community

The Visiting Nurses' Association agreed to give supplemental care. The family would have to secure full-time nurses

on their own through the professional registry. The supervisor of the local V.N.A. warned the nurse-observer, "Some private duty nurses feel the family can't do a thing and that only a nurse can do care for the patient. They don't give family credit for a penny's worth of brains." She also said that her greatest fear was that every time something went wrong, the phone would ring, and they would expect a nurse to run to the home. She explained how the V.N.A. had only so many nurses for a community, and week-end duty was compensated by giving time off during the week. The nurse-observer said that she would make it clear to the family that either they handled the care on their own, or the patient went back to the hospital.

Anthony, the only member of the family who did not agree with taking his father home, wanted to see the private physician and "get a face-to-face discussion with respect to the decision of bringing his father home." The private physician wanted to discuss this with Mrs. Wald, but did not have time for the family. He expressed exasperation with Anthony, who requested more time than he had to give and asked for more services than were realistic. Anthony was disappointed that the private physician did not have time to see him with the nurse-observer. Together, the private physician and the nurse-observer agreed on the following: (1) If there were difficulties with the I.V. or a massive problem that the private physician or nurse-observer could not help with, the patient would return to Yale-New Haven Hospital; (2) The patient and family must understand the implications and procedure; (3) If the family and patient

did not follow the diet, there would be no histrionics or coercion practiced; (4) There was a need for nurses round-the-clock; (5) The nurse-observer would make up the I.V. solutions.

The private physician also felt that Mr. X should know the cost of his care. This made the nurse-observer recoil, and she said that she would not like to be involved in telling Mr. X the cost.

(Author's comment: The strongest message to me here is the cost and limitation of health personnel resources. In our present system of health care, this seems to be a very real block to sharing. All involved wanted the patient and family to know explicitly the limits of how much they could offer. If these services were not enough, the patient was to return to the hospital. The private physician also wanted the patient to know the cost of these services. He felt this was part of the information the patient should have if he was to make decisions about his own care. The nurse-observer recoiled at this. I do not know if this was related to guilt about the high and increasing costs of medical care.

One of the private physician's limited resources was his time. When a family member demands more than the private physician can give, this is exasperating for the doctor. To the family members, not to receive requested time is disappointing. Some feelings around health professional resources expressed here are fear of over-demand, exasperation at over-demand, recoiling at making the cost known, and disappointment at not receiving.)

The nurse-observers feelings on the morning the patient went home

I felt absolutely floored by the fact that the patient will be discharged--knowing the chances of getting back in again in an emergency are nil. I feel hospital staff are "pulling out" while Dr. ___ sees me as an extension of hospital team, and this literally puts me on my own. Are they trying to make it extra hard and punish me for interfering with the system? The system seems to say to Mr. X "If you are usable for research you can stay, or if you will die quickly you can stay. But if you are dying slowly not only can you not stay, we want to wash our hands of you. Now get out! Here's a lot of equipment to keep you going twelve days--just die within that time, please."

One psychiatrist's view of how the situation should have been handled

The head nurse reported about a psychiatric conference on the ward about Mr. X. The psychiatrist told the staff that he thought they had done disservice to the family to send this man home with I.V.'s and a two week supply of things with the idea that if you do thus and so he will live, but if you don't, he will not live. He felt that instead of the medical and nursing staff taking responsibility for this man's life and death, the staff passed it onto the family. The staff should never have done this. Instead, they should have pulled out the I.V.; sent the man home; told mama to feed him anything she wanted, for he was only going to live for three days anyway. They would have been happy, and the guilt would not have been on their shoulders. The patient would have died within three days and it would have been over by now. He said he was looking at this from a psychiatrist's point of view, i.e., what would have been good for the mental health of the family. The staff doctor, from a medical point of view,

felt that he could not do this. He felt he had to keep this man alive as long as he could.

Leaving the hospital and going home

Although the spirits of the nurse-observer and Anthony were very low, and the staff were formal and hostile, Mr. X was exuberant as he was wheeled down the corridor, waving to staff and other patients. Once in the car, his eyes feasted on everything he saw--new buildings going up, landmarks in Norwalk, and tears came to his eyes as he was driven up to his house. He crossed himself as he saw the madonna on the lawn of the house. In his living room, while he took off his outer clothing, Angelo made a fire in the fireplace, his wife made him a bowl of chicken soup, and all but Anthony relaxed.

Feelings after the patient went home

The staff doctor, looking very tired, said he was sorry he had ever let the family get involved in making decisions: "It's the doctor's prerogative to make decisions. The family shouldn't dictate to us." He felt the family was forcing him into a decision which he did not know was right. He was vacillating and finally took a stand, saying, "Look, I'm in charge of this case and this is the way it's going to be." Until then, the family had been telling him what to do instead of his telling them. The nurse-observer felt the question of who decides was important, but was not sure what the right answer was.

The staff doctor also felt there had been a polarization of the family on one side and the nurse-observer with Anthony on the other. Instead of a united front from the staff, the family got two separate messages as to the desirability of discharge. So many feelings were aroused in the participants that the patient and his interests were lost sight of until the very end. He felt the nurse-observer was naive about unsettled financial arrangements, discord in the family, and physical care of the patient. He felt the nurse-observer was being unfair to herself to take all the responsibility. The staff doctor felt that more time should have been devoted to teaching the family how to care for the patient before he was discharged. He felt that it was unfortunate that the nurse-observer voiced her own feelings of doubt with the family. The nurses were disappointed that the nurse-observer spent more time with the family than with the patient. The head nurse felt that everyone was in a hurry to get the patient home and appease him in this way. She acknowledged that the patient wanted to go home and die there, not caring how long he had to live, but wanting to be at home.

The nurse-observer felt that she had moved too fast for easy relationships between the rest of the staff and herself, but everyone sensed the moment of death would come before the patient could be sent home. The nurse-observer related some of the tasks that had kept her occupied: (1) check with the V.N.A.; (2) make sure the family was willing to participate; (3) inform the private physician; (4) get the equipment

ready; (5) check into finances. All this pulled the nurse-observer away from the patient and involved her with the family. The nurse-observer mentioned the enormous delight in initially working with the staff on the unit, but that she and the staff almost ended up clouting each other on the head by the time she left. She felt there was a crisis situation which needed to be negotiated carefully and slowly, and that there was not enough time. The head nurse said she was unhappy with the decision because she felt to send the patient home was the kiss of death. She did not know that there would be nurses at home around-the-clock (nor did anyone else know, until later). The nurse-observer felt a deficiency in the hospital handling was the language barrier. She said, "I related to Albert and Anthony and got my information through them even to the extent of finding out how the patient felt. It wasn't until the day we sat down with the interpreter that for the first time I realized I had gotten some feelings from the patient." In the process, Anthony was angry, and the nurse-observer speculated that this was because he felt out of control of decision making after this function had been restored to Mr. X. Once the patient arrived home, he had been happy. He said that the hospital had been like being in jail.

(Author's comment: Who makes the decisions? Is this the doctor's prerogative? The nurse-observer felt this to be a very important question.

I would like to quote from what I feel to be similar dialogue over the issue of who makes decisions. This quote

is from the novel The Cancer Ward by Aleksandr I. Solzhenitsyn. Kostoglotov (K.) is the patient and Dontsova (D.) is his doctor.

K.: "Why do you assume you have the right to decide for someone else? That's a fearful right, and hardly ever leads to good. You ought to be afraid of it. It is a right not even given to a doctor."

D.: "But it is the doctor's right. His, first and foremost!" cried Dontsova with conviction. She was angry now. "Without that right there could be no medicine at all."

This is a Russian novel. The West often seems to project our most negative aspects on the East, and, I am sure, vice-versa. Is there a choice? Can there be medicine if the doctor does not have the right to decide for someone else? I think there can be. This type of medicine seems to demand more personal involvement of feelings and time. The nurse-observer noted that decisions seem to have a crisis nature where feelings are involved. This may be our own unfamiliarity with dealing with feelings. Yet feelings of patient, family, and doctor over and over again influence decisions.

Where so many persons are involved, there are often different views about what is important enough to influence decisions and actions. Since no other person involved in the medical care of the patient can fully understand the medical-scientific aspects of an illness, the doctor has been the one to make decisions. This placing of decision making in the doctor's hands has made science the most important value in treating human beings. Others involved in the care of the patient might place feelings above science. Perhaps neither is totally correct. What is needed is a dialogue between those involved.

This takes time and may be painful. There is relative ease in a rational discussion of the most effective treatment of an illness. There is relative pain in a discussion also filled with feelings, that seeks to choose the most effective treatment for the whole human being--not just his illness. Furthermore, the process of decision making has as much influence on the outcome as the decision itself, even if the best possible decision has been made. One should not cure bodily illness at the price of psychological infantilism or worse invalidism.)

Sharing information leads to a more active role by the family

The staff doctor explained how the family seemed to be giving the staff dirty looks, making the staff feel uncomfortable. All the staff tried to stay away from the patient as much as possible and make no unnecessary trips into his room. The family had even been refusing to let the staff draw blood. A neurologist was asked to see Mr. X as a consult. A neurology resident came first and was told by the staff that they didn't want to do any diagnostic studies because they wanted to avoid putting the patient through anything unnecessary. The staff thought the patient was dying and that protecting him from unnecessary discomfort was the best thing to do. They merely wanted an opinion about what was going on with the patient. The neurologist made a few reasonable suggestions that the staff had already thought of, but decided not to do. The staff doctor felt that it was unfortunate that the neurologist indicated his feelings to Anthony. Anthony, who only that morning had refused to let the staff draw blood,

now confronted the staff doctor, anxious to have a spinal tap and a certain blood test done. Anthony overheard a statement that the blood test could not be done that night because the technician was not available, and was disturbed that a test was not being done that night that might help his father. The staff doctor explained to Anthony that even if the blood test were done, this would not significantly change the treatment of the patient, and could wait until the next day. The staff doctor said, "That's when I realized that I found myself in a position I had never been in before. I was taking my cues from the family." The head nurse said, "That's why I said we were spoiling them. I wonder if we would have gone as far if this were some derelict they had pulled off the road with no family. I don't think so. We've been pressured constantly by this family." The nurse-observer said, "That doesn't bother me though. I like to see a family take a very active role if possible. What I am concerned about is if the family does take an active role, can they carry this out and feel comfortable."

(Author's comment: The family heard (shared) information that ordinarily stays within the staff. To a family member this information is associated with strong feelings and fantasies unless rooted by health professionals to reality. The consult was obtained seemingly without the patient or family's permission. The reason seemed to be to satisfy an academic interest in the patient's illness. It seems that there should be an equal interest in the feeling processes of

the patient and family. Also, if the family receives information from consultants, can the family not also participate in the decision making? In this case, the patient was semi-comatose. If the patient were not, then the same question should be asked about the patient's role in the decision making. Who has the "right" to make a decision when the patient is comatose--the family or the doctor? As the family or patient take a more active role in decisions, the doctor's role becomes less of absolute authority and more of a consultant who aids the family and patient in making decisions. Each person, whether a family member or patient, could take a role as active as they feel comfortable doing. This incident, like many others in the data, seemed to show that as more information is shared between the patient, family, and health professions, the patient and family demand more of a part in the decision making. This takes time.

Over and over again those people who advocate non-sharing cite lack of time, limitation of resources, legal responsibility, and routine as reasons that sharing is not possible. But health care without sharing leads to actions being done to an illness rather than with a person, resulting in episodic care of illness rather than treatment of the whole person. As more persons are involved in sharing (as a system becomes larger in the number of individuals involved), orders of priority must be set. Whose feelings come first, and whose decisions are most important? My feeling is that medical care should place the patient's feelings and decisions first.)

The patient at home

The patient was tremendously pleased to be home, but the family's ability to cope with having him at home was not always sufficient. Even while the nurse-observer was unpacking and arranging equipment, Anthony had a petit mal seizure. Although on the first day visitors (especially family members) flowed into the house, they soon came less frequently--especially Anthony. One son, Roberto, took most of the responsibility at first, helping his father and mother effectively; but soon his wife became angry at his involvement because he was spending too much time at his father's house, and she left him to return to her mother. The youngest son, Angelo, suffered a severe "viral attack" and became bedridden. Since this affected his digestive system, the family's immediate reaction was that he had the same thing his father had. The wife did not sleep for two nights and refused to go to bed. The nurse-observer felt that Mrs. X, in her mind, had made the connection between the nurses and supplies and how the funds were being eaten up. She seemed to have translated this into something quite concrete so that she watched the nurses to make sure they would not eat the supplies.

The patient had a slightly increased temperature, but death was not expected to intervene before a decision would have to be reached as to whether or not to return him to the hospital. He had four or five days at home that were terribly important to him, in which the family took great pleasure in being able to give to him. Altogether, he had been home over

a week at this point. The nurse-observer described him "sitting in front of the fireplace and directing his sons in the snow removal outside. He can walk around the kitchen with his I.V. pole and tell them all off, just exactly what to do."

One problem was that though the patient enjoyed being home, the family's capacity to cope was inadequate. Another problem was the bacteremia resulting from the placement of the I.V. Part of the difficulty was the tremendous cost. The patient's catheter added to the problem, necessitating round-the-clock nurses. While an insurance policy of \$8,000 was available for nurses, it cost \$1,000 per week for the nurses alone, and the insurance paid only eighty percent of this cost, the other twenty percent being the family's responsibility. No one in the family could pay this except Anthony, who did not want his father home and refused to chip in with his brothers and sisters. The following came from a conversation on this issue by members of the IDS:

Doctor: Are you saying it's more economical to be in the hospital than at home?

Nurse-observer: Yes, because Title XIX pays for that and it does not pay for nurses at home. That's the irony of it.

Nurse: . . . if it's more expensive to keep him at home, welfare would not pay it unless we move him into a hospital where they would take the least expensive route and that's it.

Doctor: So we really aren't talking at all about a medical decision; we're talking about a perfectly "practical" decision.

Nurse-observer: No, you're talking about a medical decision that's one issue of it and then the other decision is the medical decision in the context of the family's ability to implement that medical decision, and include their ability to finance this and society's ability to finance this.

One of the nurses attending noted that the health professionals seemed to be doing something to the patient that had been done in the past. She said, "We don't ask the man himself what he wants in the situation. Mr. X himself I think might have, given the financial facts, been able to come to some conclusion himself." She noted that he still was the patriarchal leader of the family and if he had the information, might help in making the decision as to when and where he was to go.

The costs would not have been so high if the nurses were not needed to handle the I.V. The family had, in fact, been partially trained to do the nursing while the patient was still in the hospital. At the last minute, however, the family and staff panicked about caring for an I.V. and arranged for nurses. The emotional burden of watching a technical apparatus such as an I.V. connected to Mr. X was great.

Another nurse at the IDS conference felt that a family should have a patient die in the hospital unless the patient required only minimal nursing care of bed and bath. It was also mentioned how difficult it was to control a home situation as opposed to the hospital. In the patient's home, health professionals realized that it was the family's home, and they did not dare to make corrections, whereas in the hospital it was the other way around.

The nurse-observer felt that everyone but Anthony had been happy with the patient's first seven days at home. But at this IDS conference, it appeared that both the patient and family were getting less satisfaction, and it seemed as if a change were needed. The nurse-observer felt this situation raised the issue of how to meet both the patient's and the family's needs. The staff doctor felt that if he had to do this all over again, he would not do it much differently. He said that he probably would make the same mistakes, acquiesce to the family in the same places, and place the patient's interests above the family's interests even if sending the patient home was going to cause problems in the family. He did not realize that this would cause as many problems as it did. The nurse-observer felt that she would not want to get involved in such massive technical intervention and would also like to move into decisions more slowly. She also mentioned the system in England at St. Christopher's Hospice, where a patient could go home, but when the situation at home became overwhelming, he could always return to the hospital; from the hospital, he could always go home again when he wanted. In other words, no decision was final and irreversible.

If the patient were to stay or return home, the nurse-observer felt that Mrs. X would need tranquilizers. The staff tried to look at what could be disturbing Mrs. X. They felt that she probably got her joys out of life from being a condescending woman, feeding her husband properly, and cleaning her home so that Mr. X could appreciate this. Nurses had come

into the home and taken away from her these two expressions of her loving concern for her husband. Could she be jealous?

The patient at home participated in a decision in which he was given much of this information. He decided to return to the hospital. At this time he did not want to go home anymore, because he saw what this had done to the family. It was also hard on him at home. He knew he had the opportunity to be home, but realized financially, socially, and psychologically that this was a drain on everybody. It is important to note, however, that wherever he went from this point on, he would be participating in the decision.

(Author's comment: The description of the patient at home clearly indicates how the patient cannot be viewed only as an illness. In the home setting he is apparent as a whole person; his family relations are also apparent; family and community resources must be assessed.

The priorities mentioned by the doctor are a beautiful statement arriving at a workable model for a sharing system of health care. The patient's needs came first, the doctor acquiesced at times to the family, and the patient's needs were considered above the family's needs except when extreme harm was being done to the family.

In this decision, the health professionals caught themselves in the process of not speaking directly with the patient. And in fact, when the patient was given all the information, he was able to make a decision that took everyone's feelings into account--a decision that was even somewhat of a sacrifice by him. Yet what an extraordinary difference exists between

a person being able to make a sacrifice willingly, as compared with something being taken away from him. One way allows the person to act as a mature individual. The other way leaves a person infantilized while others act for him and do things to him.)

Some feelings on being left out of decision making

When the patient returned to Yale-New Haven Hospital, he went to F-1, an acute medical floor where medical students, interns, residents, and groups of consultants cared for the technical, medical intervention of the patient. When the nurse-observer, who was giving direct nursing care to Mr. X approximately twelve hours per week, asked if she could participate by listening to a discussion by doctors about a medical decision, the staff doctor said yes. The nurse-observer notes:

I felt as if he really didn't want me to listen. Then he and the other doctors were discussing the possibility of a bowel transplant. At this point I was hesitant to interrupt because of Dr. ___'s "coolness," but I decided I would, and said, "I thought the bowel transplant had been discussed by Dr. ___ and Dr. ___ and that they felt Mr. X's blood vessels were not adequate for the procedure." Dr. ___ answered that they were only talking figuratively, and turned his back on me. I continued to stand there and when the group moved slightly, repositioned myself in the group. They had just decided to write the suggestion in the chart about the arterial-venous shunt. Again I interrupted, though I didn't feel as if they welcomed this. I expressed my concern that such a shunt might make him no more eligible for a continuing care home or a nursing home than his present I.V., and that a procedure to shunt might make new problems which ultimately could not be solved, just as the original procedure done by Dr. ___ created problems that we now could not solve. Dr. ___ did look at me and nod in assent--for a moment I thought I had reached him. Then he said, "But he's out of veins now. We must solve the immediate problem."

When the nurse-observer said to the staff doctor, "What

good is it going to do him?" he said, "Well, I have to take care of this man's pain at the moment. I've taken the hypocratic oath." The nurse-observer said, "Well, what is his pain?" Dr. ___ said, "He doesn't have any." The nurse-observer: "No, in general what is the pain that you are responding to?" The doctor said, "The fact that he has to be on I.V.'s for therapy." The nurse-observer did not feel that the doctor's vision encompassed the whole problem.

This situation was more typical of F-1 than the former ward. Some quotes by the nurse-observer would be helpful in understanding the effects of trying to share information and feelings but being left out of the decision making process: "I don't make any pretense about not being emotionally involved. In fact, I really feel as though this (involvement) is essential." This does create problems when she noticed a difference greater than she had expected between what she felt the patients really needed and what they actually received.

I'm so appalled that my emotional involvement and my inability to be part of the decision making process leaves me so frustrated that I'm really in great pain. When pain, anger, and depression get bad enough, I think it renders me less competent as an observer . . . I'm almost rendered as immobilized as the patient is. Now this gives me a much better insight about how the patient and family feels I'm just nearly livid when I consider what the professionals are doing.

The nurse-observer sought consultation from a doctor as she attempted to master these feelings. He commented:

When you concern yourself with educability of a doctor or a nurse or a family member or the patient himself, you have got to examine this in terms of the size of the system. If you have confusion, as we do, in our

modern medical centers, there is no hope of a way of approaching the measurement, evaluation, and continuity of relationships. . . . I think the work is undoable here for obvious reasons--the jealousies, the impossibilities of rotation, the diffusion of authority, the lack of supporting structure for this kind of research. The researcher must be sanctioned by the power . . . that must say to his staff or to whoever else comes in and uses the institution that this is work of top priority.

The nurse-observer also felt that medicine was directed so much toward making people live that a doctor becomes suddenly horrified when he realizes he is participating in a study of dying.

(Author's comment: When attempts are made to cross professional disciplines to share information, this allows decision sharing as a possibility. Negative feelings about interdisciplinary decision sharing will be a block unless dealt with openly.)

Serendipity

In the remainder of his life, Mr. X was involved in a number of systems of health care. The following are some short incidents and/or conclusions that helped me to understand more about our health care system.

The Egg Situation

The patient had not eaten anything but special food mix in over a month. The nurse-observer came on duty and her knowledge of a decision having been made came when the patient looked up at her with an egg in his tray. The nurse-observer scurried around first to the doctor's order book, where no order was written. One of the doctors on rounds mentioned that this change in diet had been arranged the day before, but the

dietician with whom this had been arranged was not in yet. This produced an enormous amount of anxiety and anger in the nurse-observer. This became known as "the egg situation"-- an example of a decision being made but the information not being shared.

Who's keeping house

The head nurse on the ward and other ward nurses agreed that one of the problems was that nobody really knew who was running the place. They encouraged the nurse-observer to share her anxiety with them sooner, rather than sitting on it. The nurses were not even certain which of the two doctors was caring for Mr. X.

It's not that they're in a position that they don't want to, but that they're in a position where they can't

The nurses on F-1 were feeling angry because Mr. X was receiving better care than anybody else. They pointed out that there was another man dying down the hall that the nurses felt even more emotionally involved with and were able to do even less for him. Every little thing that Mr. X asked for took up time and allowed them to do less for others. This is the theory that "it's not that they don't want to but that they're in a position where they cannot." The nurse-observer said she could not do what they were doing. Their attempt to remain humanistic and at the same time care for all of the other responsibilities overwhelmed her.

(Author's comment: Nurses are emotionally involved with patients. So are doctors and others that come in contact with

the patient. The nurses feel like they really would like to do more. This is just so natural a feeling for one human being to have for another. The greatest deficiency in a hospital is not the "limited number of professionals" but time for all those involved just to be a person to another person, to show that there is real caring, one human being to another.)

How to value a family's feelings

A placement decision was being made. The family did not want the patient to be placed in any of the institutions mentioned by the health professionals. The nurse-observer felt it would be very hard to say that she was listening and valuing the family's feelings but that the patient still had to go to one of the places even if the family objected. Staff feelings are important also. It is one thing always to listen to a family's feelings and consider them in making decisions; it is another thing to have the family's feelings dictate without question what is to be done.

Shut the door

This note was recorded by the nurse-observer when working on F-1:

One instance I asked to listen in on the doctors' rounds. It was all right as long as I stood there and listened, but when I tried to contribute something the doctor turned his back on me to keep me out of the conference. The second situation a couple of days afterward when the doctors were right outside the room and the door was slightly ajar. I opened the door a little bit so that I could listen and the doctor told me to shut the door. Now, you know, I could probably have gotten on the other side of the door, but what I'm saying is that these are some of the indirect ways that doctors will tell me to stay out"

Question: How can nurses, who may be in direct touch with the whole patient and family, offer relevant observations that have direct implication to the overall medical treatment decisions?

Only so many hospital beds

The primary concern of the staff physician was that the patient should be taken out of an acute hospital bed. He was not particularly concerned where the bed was that the patient was being sent to. The social worker was given the job of relocating the patient. Time can be short and there can be unforeseen limitations in placement possibilities. If the social worker runs into a problem finding the best bed, then she has to find any bed because the doctor has placed demands on her. This separation of the function of making decisions and performing tasks is not always in the patient's best interest. The social worker is motivated more by the doctor's feelings than by those of the patient.

Integration of feelings is painful

The nurse-observer felt that both the doctor and the head nurse on one ward (H-5, the first ward) came closer to integrating the humanization or feeling factor into decisions and care than the doctor and head nurse on F-1. But it was quite clear that there was a tremendous amount of pain in effecting this integration. Those involved experienced "bad feelings" of depression, frustration, and anger. Decisions with intense feelings had a crisis nature to those involved.

Setting as an independent factor affecting mood

The nurse-observer felt that not all anxiety and depression were directly related to the patient's dying. The ward setting, that led to the infantilization, immobilization, and isolation of the patient, seemed to have a tremendous impact on the patient's mood; the setting itself led to feelings of anxiety and depression.

Trouble-maker

When the nurse-observer tried to bring the patient's and family's questions and misunderstandings into the open, she was regarded as the cause of the trouble by some of the other health professionals. When she found discontent (whether the patient's or the family's), she tried to make this known. She also encouraged any persons who were dissatisfied to express themselves to others. She did this in search of the real wants and needs of the individuals involved. When she did all of these things, she was regarded as the source of the trouble. The other health professionals said such things as, "We never had this trouble until you came along."

I am reminded of a classmate's father who, in taking over a regional venereal disease center in New Jersey, reported all cases. The county's ranking according to the incidence of venereal disease rose to practically first in the country. Everyone blamed this man as if he were personally responsible for all the venereal disease. The county's ranking descended again after this, but only after real measures to combat and

treat disease were taken to meet the situation. In this sense, the nurse-observer was seen as the same type of "trouble-maker" that my classmate's father was: a person who speaks the truth as she sees it.

Feelings should be expressed directly

The nurse-observer became very sensitive to the feelings of the patients she was caring for. If one of these patients had negative feelings about a decision, care given, or another person, the nurse-observer found it more effective if these feelings could be expressed directly to the person concerned. For example, it was important for the doctor to know the patient's feelings so that these feelings could influence the doctor's decisions. If a decision had already been made by the doctor and the patient was dissatisfied with this decision, it was much more effective for the patient to tell the doctor directly than to withhold his feelings or work through an intermediary.

Sharing information, feelings, decisions, and tasks among staff leads to thoughts of how to include the family in sharing tasks

A nurse and a ward secretary (who was Italian and frequently acted as interpreter) came to the patient's room to ask if the secretary could make zabaglione, an Italian egg dish, for the patient. Mrs. Wald thought that would be wonderful. After the ward secretary made the zabaglione, she brought it to Mr. X, who ate it with great pleasure, to the delight of the secretary and the nurse-observer. Later, the patient's doctor asked,

"How did it go?" Both doctor and nurse were delighted as the nurse-observer described the big smile on the patient's face as he ate. Then the nurse asked if, in the future, the patient's wife might like to make this for him. The nurse-observer thought this would give her great pleasure.

This sharing of the task with the wife brought both her and the patient much pleasure. Even small decisions that allow the patient and family to share more can greatly change the quality of the experience in the hospital.

Patient asked for his room to be rearranged and the staff did it according to his wishes

While this does not seem like such a big thing, some places might not allow even this because of routine. This made the room much more personal to the patient, and the process allowed him to be effective in changing his environment to his pleasing.

Patient-tasks

The nurse-observer attempted to make the patient more independent by having him bathe himself. The patient, however, broke out in a tirade. He said that no one caring for him ever made him wash his legs before. When the nurse-observer explained why she had let him, he said that he was not strong enough yet. She then bathed him. Sharing information for a decision lets the patient reject a decision. Also, by listening to a patient when he is angry, his anger can be reduced.

The more information gathered around feelings of the patient, the more health professionals will understand the patient's needs. However, if the patient's needs and expectations are greater than the health professionals' ability to meet those expectations, this will lead to agitation and frustration for those involved.

The nurse-observer, arriving in the morning, checked the nursing notes, which stated without explanation that the patient had been agitated the previous night. When asked about this, the night nurse did not know what it was about. Another explained that the patient's supper had consisted of only dry crackers and mashed potatoes, with no fluids, and this upset Mr. X very much. Another nurse volunteered that Mr. X wanted his urinal emptied each time he used it, but that she did not have the time to do this, as she had other patients to care for also. The nurse-observer responded that she could understand how difficult this was for the nurse.

An example of sharing

Mrs. X rode up with me (nurse-observer) this morning in the car. She appeared very tired--her eyes lack lustre, her skin is pasty gray-yellow. It was exceptionally difficult for me to understand her, and she, seeming to sense the difficulty, made less effort than usual to talk. For fifteen minutes she said her rosary, and this seemed to put her at ease--and truth to tell, put me at ease too. The rest of our conversation was nonverbal gesturing--"see the big truck," "that's a nice house," etc. This level of conversation was mutually satisfactory, I think. She did count the number of months (eight) her husband had been sick, and tears came down her face as she said, "Too much, too much!" I reached out to her by holding her hand and saying, "It's been very hard. He's been very patient."

When we arrived, Mr. X had just finished breakfast. He broke out into a broad smile. Mrs. X hugged him and beamed all over. She took off her boots and put on bedroom slippers. . . . He asked if he could have steak again today and then Mrs. X said what about a little squash. We discussed different sorts of vegetables he likes (spinach, escarole, tomato) and I said I would ask the doctor.

Mrs. X began to help me getting ready for the bath and in fact began to wash his face. So I said would she like to bathe him and she was beaming. So I showed them the bell and went out to take care of charts and so on

When the nurse-observer returned to the patient's room,

Mrs. X had done all of Mr. X's bath and was chuckling over him. I got more cream and the linen, and sort of acted the nurses aide to her, which all three of us enjoyed. She wanted to help me make the bed, but I said she should rest. But with great pride she showed me where the button was on the electric bed to raise the level of the bed so making it easier to make.

(Author's comment: Comments seem unnecessary compared to the description of the experience. It seems really beautiful for a health professional to view her goals in terms of the patient's and family's feelings rather than in terms of getting a task done. In fact, the work was done with much less investment of time and energy on the health professional's part, yet all involved felt very good.)

Decision made by those who agree

In deciding where the patient was to go next, the social worker worked with the one family member who agreed with her. The nurse-observer pointed out that another family member disagreed, and asked if there would be a conference where everyone could get together. The social worker felt the conference would be unnecessary because she had already spoken to one

family member. To have another meeting would have taken more time. Over and over again it seems easier to handle disagreement and dissatisfaction by remaining oblivious to it.

Non-acceptance of death leads to search for alternative treatment procedures

Members of the health profession, the patient, and the family vacillated between seeing the patient as surviving and as dying. Slowly, however, they began to accept the patient's dying. Anthony, who could not accept this, had the least actual contact with his father. Instead, he spent his time with the staff searching for alternative treatment procedures. Included in this search was the consideration of a bowel transplant in which Anthony was sure that one of his brothers could donate part of his bowel to his father.

Anthony's behavior seems to be typical of the role taken or assigned to at least one member of the family. It is also typical of each individual--whether patient, family member, or staff member--that non-acceptance leads to task orientation and searching for alternative treatment procedures. This person will also be the one that is most upset by apparent mistakes or mishaps in treatment, and who will be searching for someone or something to blame for the patient's death. This person's guilt seems too great to accept within himself and there is a need to fix blame on something outside himself.

Don't run my life

In terms of decision making, Mr. X, his wife, and two

sons (besides Anthony) were controlling what would happen next. This took away from Anthony the control he had had before the patient and the rest of the family knew what was happening. Anthony wanted some further treatment, such as a bowel transplant, although the rest of the family and the patient did not want anything to do with this. The father felt that Anthony "was a fine boy but he's not going to run my life, not as long as I'm alive."

You ask me questions that I can't answer and it makes me feel uncomfortable

The nurse-observer writes:

Dr. _____, an intern, said, "No, I don't have time to give you (the nurse-observer) other than what you can ask here and now. You ask me questions that I can't answer and it makes me feel uncomfortable." This couldn't have been more direct. She was trying to be helpful in expressing just how she felt. I needed the answers to things that either she had no answers to, or because she was caught up in the large mass of people, side by side, influencing the decisions but not directly making them. She saw herself powerless. And I feel the nurse's role is more powerless than hers.

"Cura Naturalä"

At the end of the month the patient was transferred to the hospital in his hometown and returned to the care of the suburban specialist in internal medicine. The I.V. catheter either fell out or may have been withdrawn by the patient. The surgeon attempted to reinsert the catheter in the femoral vein, but was not successful, to the relief of the patient. When the nurse-observer, who continued her care for the patient in this hospital, saw the patient the following day, he

beamed as he said, "This is the way I want it--cura naturala." However, he seemed very weak, and asked Mrs. Wald to ask the doctor for something to make him strong. Injections of B12 intramuscularly were started.

The birth of a grandchild

While Mr. X was in his hometown hospital, his daughter delivered a baby in the maternity ward of the hospital. The nurse-observer asked Mr. X if he would like to see his grandchild. The nurse-observer said in her notes, "He almost leaped off the bed as if to go on the spot. A student nurse said that this wasn't usually done, but volunteered to find out if it could be done. The ward secretary in the maternity unit said, "No!" The student nurse suggested that a better answer might be obtained from someone else but seemed uncomfortable in pursuing this herself. The head nurse on the medical floor was not enthusiastic about this but did tell the nurse-observer where she could reach the head nurse of the maternity ward. Both the head nurse and the supervisor of the maternity ward initially said, "No!" When the nurse-observer explained, however, that Mr. X probably would not live much longer, they were both moved and explained how this could be done. The nurse-observer asked them to check with Mr. X's daughter (the mother of the baby), who upon hearing about this idea was delighted.

The nurse-observer went to the patient's home to pick up his wife, stopped by a food store to pick up some juice Mr. X had asked for but the hospital did not have, and also got her camera.

Then Mr. X, accompanied by his wife, was brought in a wheelchair to meet his daughter at the window of the nursery, so that the daughter in one wheelchair and the father in another could see the child together. The nurse-observer notes, "This was a very touching moment for all of us. Mrs. X was moved to tears (and all the rest nearly so) but Mr. X had great joy in seeing the baby as did his wife. Then he turned his full attention to his daughter Angelina. They embraced one another as wheel chairs were side by side."

(Author's comment: Again comments are rather pale compared to the actual experience. An opportunity for the patient to express his feelings and to do a meaningful act were almost blocked by a number of persons who relied on rules, regulations, and standard procedure. These persons cooperated only after the nurse-observer reached them on a feeling level. The sharing of information and especially feelings was very influential in this decision. Can you imagine how a patient would feel if the nurse-observer had not been there and the patient encountered all of these obstacles himself? I can imagine that he might feel angered, depressed, resigned, helpless. Sharing an experience like this is a beautiful gift to all who are involved.)

What are the goals

Mr. X's I.V. had come out, he was still having diarrhea, and he was getting regular meals. The staff knew such meals could increase the diarrhea and dehydrate the patient even more. Not only the information but also the feelings should be noted

in the following that the nurse-observer wrote:

Meanwhile I talked with the student nurse who had been working on the diet for Mr. X. I had been somewhat appalled at the regular meals being served him Sunday and today. I asked her what her goals were. "To get him better and to get him to gain weight." I asked her if she thought this very realistic, and how she would feel if he didn't get better since this is a very likely outcome of the current regimen (i.e., no I.V., no formula, regular diet) and she seemed startled. Then I suggested that another goal might be to make him happy--and that our present regimen would do that and seems to be successful.

(Author's comment: The health professionals may be appalled and startled, but the patient is happy. Decisions about goals should be made knowingly. If not, this can lead to much more guilt later on when the decision is not viewed as a conscious choice of goals, but as a mistake in management.)

Everyone knows that Mr. X is dying

Doctor: "I don't know how much the family told her (Mrs. X) along the line of hope or lack of hope. I've tried in all fairness to let Anthony and one of the other sons know what my feeling is--that there's truly no hope for their father and that he will die because maybe it's selfishness on my part but I want to protect myself when the bottom falls out, which it will. . . ."

Nurse-observer: "But for example, even the oldest daughter Josephine who's not educated at all, quite a nice person, stopped by the other day when I was bringing Mrs. X home and Josephine stopped by and said to me, what I thought was very beautiful--"Don't feel bad if he dies; you've done everything you can." And then the next thing she said was, 'You know, we've met so many nice people while he's been taken care of. . . .' as if to say, "Out of suffering comes some good." And Carmella knows this, Albert knows this, Angela knows it, Anthony knows it, Mrs. X knows it, Mr. X knows it. There isn't anybody who is I think living in a dream world."

Nurse: "But there isn't anybody left alone in the end except Mrs. X. They all have somebody else."

Nurse-observer: "That's the problem. And the problem right now is that she's leaving Mr. X alone because I think part of the problem may be that she's angry at him because he's leaving her with a lot of unsolved issues yet she doesn't want to be mad at the poor little weak guy at this point, especially because she loves him so much. They do have a close relationship and their life is so simple."

Wife stopped making food

When the wife came into the hospital and saw the food her husband was getting, she thought the staff was starving her husband. She became angry and brought in two meals a day for her husband. He really enjoyed them. But when she saw the diarrhea the patient was having, this scared her and she stopped.

(Author's comment: The decisions both to bring meals in and to stop bringing meals in were based on the wife's feelings. The patient's feelings were not taken into account.)

Doctor's philosophy

Well, my philosophy has been, my approach has been, anything to make this man happy I will do provided I don't run at odds with the family I've been caught for a long time and will be til the bitter end. That's why I wanted to go along with almost anything strictly pragmatic. I think it's the only way to be here. Anyone who disagrees, I'd be glad to talk it over with them because I don't--there's no solution and what we're trying to do is keep this man comfortable and happy and at the same time without causing undue burden on those who are mostly involved with this man and that's the hardest thing. It's a very narrow trail that you tread here and you try not to become emotionally involved yourself because then you become angry. The family's allowed to get angry but you're not supposed to.

You don't play God. You can't. You don't say "Turn off the machine, let him die."

The patient had mentioned to the nurse but not the doctor that he wanted to go back home. The patient had come into the hospital this last time "because his potassium fell out," according to the doctor. If he went home this would probably happen again. The doctor said that under a medical urgency or necessity he would have to bring the patient back to the hospital to replace what he was losing. The following interaction took place with the doctor:

Question: "What would happen if you didn't?"

Doctor: "Well, he'd just develop cardiac abnormalities and just weaken."

Question: "Would he die?"

Doctor: "He might die."

Question: "Why not let it go?"

Doctor: "I can't answer your question. I don't think it is fair."

Question: "What question?"

Doctor: "Why not let it go, wasn't that pretty much it? Where there is desire on the part of the patient and family to go on. I've been practicing medicine for a number of years and I take a very passive approach to the problem. I think most doctors do. You don't play God, you can't. You don't say turn off the machine, let him die. If there is desire on the part of the family and patient to squeeze out what is remaining, it's not up to me to decide what to do No one wants to have an intravenous, but he'll accept it if I say he needs it, I'm quite sure of that."

Have we done everything we can as people?

A: "What I was saying, you know, I think relations, the husband and wife, if things are breaking apart, do have to be helped to hold things together. But if she is going through premature grief or something."

B: "It's really a separation."

A: "It is getting adjusted to a separation and she's hurt because he's leaving her and she withdraws a little. We can't turn that off nor should we."

Nurse-observer: "No, I'm not trying to turn it off, I'm merely trying to ease it or help it"

Doctor: ". . . if you're doing a job and you find there is very little you can do, you want to make sure that you've tied up loose ends that should be tied up such as, you're doing everything you can in practical sense medically speaking, and nursing-wise, but have you made sure that the family is properly cared for . . . your conscience says are you being careless, are you being thoughtless about people who are grieving? Am I right?"

Nurse-observer: "Yes, that's the way I feel."

Doctor: "Have we done everything we can as people?"

How much do you do beyond which is useless medical intervention that really will not pay off?

The doctor felt this was indefinable. He just did the best he could. Yet some decisions had been made, for example, the decision of not putting a special catheter in a larve vein to temporarily put fifteen pounds on the patient (a decision later reversed). The doctor said, ". . . it's a matter of conscience. Are you doing more harm than good?" Someone else commented that no matter which decision is made, the doctor was never going to be one-hundred percent comfortable.

(Author's comment: Such a decision is a matter of conscience for the doctor. Are you doing more harm than good? This is a good question. But I ask: more harm than good for whom? How is this defined or evaluated? Some may view the patient only in terms of his illness and medical intervention,

others may look at the whole patient, others would define a patient as part of the family. But again, the basic motivation behind this most important medical decision is feelings, even of a moral nature.)

One last treatment procedure

Anthony and his private physician told the nurse-observer that they planned to send Mr. X to Philadelphia for a special treatment procedure, the placing of a large catheter in a large vein so that a special mixture could be given the patient who would gain up to fifteen pounds temporarily and perhaps an additional two months to live. The nurse-observer asked Anthony whether or not he knew that his father was planning to go to Italy. He said that he did know this but did not think it was very practical. The nurse-observer was concerned because the private physician and Anthony were planning one strategy, the special treatment procedure, while Mr. X and the rest of the family were engaged in joyous planning for a visit to Italy. The nurse-observer described her feelings: "In this dilemma, I feel that neither Anthony nor Dr. ___ feel that I could be of any help to them, or want any of my opinion on whether or not this is useful or not useful, and this rendered me quite helpless and irritated." At the patient's home in a conversation between the nurse-observer and the patient, when she mentioned Philadelphia,

His eyes seemed to light up and be bright, and he seemed, my impression was, that he seemed to want to go. However, when I got back to the kitchen, where Mr. X couldn't see his wife, she was in tears and she was in

whispers asking me what I thought about Philadelphia, and shook her head back and forth, and I had the feeling that Mr. X did seem to find this a good idea while she was very unconcerned about it. I, myself felt very depressed and all I could do was to give her a big hug, and then I told her that tomorrow when I came, I would get a chance to talk about it and think it through with them a little bit more.

I am worried because I am afraid that I may find myself siding with one part of the family against the other part of the family, and perhaps if Mr. X himself does want to go that again, with the basic assumption of following his cue, and this is the thing that I should do is support him in the decision to go and to help Mrs. X also go along with that decision. In my heart of hearts, I find it very difficult to give the action support. I did try to indicate to them that the treatment, as I understood it, would help a little bit and for a short time, and they both nodded as if somebody had made that clear to them, that it was for a little bit and for a short time. . . . I'm out of the decision making team, that is now made up of Anthony and Dr. _____. I was comforted at least, however, that they had discussed this question with Mr. and Mrs. X. Whether or not this had been before or after the fact that Dr. _____ decided to go ahead with consulting the doctor in Philadelphia, I am uncertain about.

A tragic-hopeful end in Philadelphia

When they arrived at the station, his father had been unable to walk up the stairs, and (Anthony) carried him in his arms to the top of the stairs. Some fellow travelers helped him find a taxi, and unfortunately, this was just at the time of a terrible down-pour of rain, so they had to go through the city of Philadelphia in the pouring rain. But for some reason they had not taken the medications with them. When they arrived at the special Institute (which was a section of the University of Pennsylvania) where Mr. X was to be admitted, the admitting officers apparently knew nothing of his coming into the hospital, and questioned Anthony about how the hospital would be paid. Mrs. X was crying, Mr. X was upset, and Anthony apparently angry and I gather it took them from 2:00 P.M. until 6:00 P.M. for him to be admitted to the ward. In fact, the family had gotten so upset, that by this time they were about ready to take him home again, in fact Anthony had just gotten a wheelchair, and was already wheeling him toward the door when the doctor with whom Dr. _____ had arranged the transfer appeared and Mr. X was duly admitted. The family stayed with him until the following

morning, I think until about 6:00 A.M., that is on Tuesday, when they took the train back and arrived home at about noon. They had hardly reached the house, when Mr. X called to say that he was vomiting and later in the evening called again, apparently had chills, and was unable to make himself understood so that the only way he could get a blanket was to call from Philadelphia to his home town in Connecticut and have them translate for the staff who were in his room.

When the patient died, no one in the family was with him in Philadelphia. "Mrs. X and daughter each felt guilty for even having let him go to Philadelphia." They said that Mr. X was overcome with homesickness at Philadelphia and was begging to come back home. This was the one time that the nurse-observer was able to talk with the whole family and have them express feelings one to the other. She felt this was the technique that she should have used more often.

Then Anthony asked me to come in the other room and I felt a little uncomfortable leaving Mrs. X's side and the rest of the family and going into a secret session with him. Especially when we had such a good chance to talk right in front of the whole family, everyone expressing everyone else's feelings. But I'm wondering if this isn't the trap I've fallen into, Anthony works outside his family, then lets them know what he's going to do, rather than work together with them. At any rate, he said that while he had originally asked for the autopsy, apparently, the hospital felt that he did not qualify as next of kin, and that in order to do an autopsy they would require his mother's signature. This he felt he could not get and so he had decided not to do anything about it. I said, "Well, I didn't really think it was of much use except of academic interest." However, apparently, he still feels very strongly that the situation was mishandled and really wants to know what his father actually died of. He feels that the heart attack was caused by the poor handling at the Institute.

Also, the nurse-observer wrote another insightful note the day before the patient's death about Anthony:

It still seems to me that of all the family members, Anthony is the one who has found it most difficult to

give up on his father, and most unwilling to discuss this. However, to look at it from the smorgasbord point of view, Mr. X did turn to Anthony at times, even though at other times, he was very angry with him and Anthony's search for a new kind of treatment or something new, I think had a great deal of meaning which perhaps the rest of us couldn't convey to him with as much conviction.

(Author's comment: Again I would like to point out the relationship between guilt and blame to acceptance and non-acceptance of death. Mrs. X and the daughter who accepted Mr. X's death to a certain degree blamed themselves or felt guilty. Anthony, on the other hand, wished to fix the blame on the doctors' and the Institute's mishandling of his father.

Also noted at this time was the manner that Anthony moved toward a secretive non-sharing of information, feelings, decisions, and tasks. I would imagine that each person there felt pain and guilt associated with the death. The rest of the family handled this openly, in such a way that each could realize that he was not alone with these bad feelings. Anthony, secretive and alone, did not seem able to feel and express the guilt within him and sought to blame others. This non-sharing seemed to be a much more destructive way of coping. This insight that came to the nurse observer at the time of death was to be the gold that shines through the darkness, and would play a significant part in her future participation in systems of health care.

As I looked into these systems, I found certain members more oriented toward quality of life, even if this meant a

shorter life. The medical staff may fall more into the former while the patient and family fall more in the latter group in some events. But no such generalization can be made. The initial staff doctor wanted quantity as long as the patient was comfortable. When he realized the patient was not comfortable, he was willing to make a decision in terms of quality of life. Although Anthony was anxious for the surgeon to try such dramatic and almost unprecedented procedures as a bowel transplant with one of his brothers giving part of his intestines to his father, the surgeon told Anthony that the operation was out of the question. So rather than stereotyping staff, family, or patient, I would like instead to present the view that quantity and quality should be regarded as opposites within each person. Each person (whether patient, family member, or health professional) wants both quality and quantity of life not only for the patient, but also for himself. Only considering one is where we may oversimplify and get into trouble.

Let me write further about opposites before returning to an example. Jung (1968) viewed opposites as existing within each one of us. Within each of us is the need to be healed as well as to be the healer, the extrovert as well as the introvert, action and thinking as well as passivity and feeling, light as well as dark, masculine as well as feminine, the adult as well as the child. When a person is strongly associated with only one part of a pair of opposites, the other part is cut off from that individual's consciousness and thrown into

the unconscious. Repressed here, this opposite is projected outward onto others. Projections of this sort can be destructive as well as negative. An individual who must always be a healer makes a very poor patient, for he will not allow himself to be healed. A person lost in extroversion may be hit very hard by inner questions. A person who must act and think may find it difficult to experience his feelings and have an acceptance of life. A person who is only associated with the child within will constantly run into an outer adult establishment, even as a person who is only associated with the adult within himself may find that he is constantly watching over others as if they were children and never participate in much of the naive fun of life.

I regard quantity and quality to be such opposites. Also hope and hopelessness, as well as acceptance and non-acceptance, can be viewed as opposites. Mr. X, who at one point said that he wanted only to be home and die there and did not care how long he lived, strongly associated himself with quality at that point. Anthony strongly associated himself with quantity. These two were bound to have a conscious repelling of each other at the same time there was a much stronger unconscious attraction of opposites. These two were destined to meet in the final decision to travel to Philadelphia for one last dramatic treatment procedure. Anthony, who had never given up hope, combined with the private physician, who had stated

earlier that not only had he given up hope but had told the family members that there was no hope. Together Anthony and the private physician urged Mr. X to travel to Philadelphia for this final treatment. Mr. X, who had want quality of life and cura naturala, met the opposite in Anthony and the private physician, who wanted an extension of quantity of Mr. X's life and attempted to achieve this with technical scientific treatment procedures.

At least Mr. X was informed and allowed to make this decision. As the nurse-observer described her feelings, "In my heart of hearts, I find it very difficult to give the support." Also, she wanted for Mr. X what he wanted for himself. She did not want to side with one side of the family against another. There must be a constructive way to share this feeling in such a system. The patient's feelings might be most important and the family's a close second in importance, but certainly the health professionals' feelings are of some importance also. I feel that these feelings can be expressed with the emphasis that the decision still remains with the patient and family. In the same way that I discussed opposites before, so do they apply here. The nurse-observer had feelings opposite to Anthony, the private physician, and the patient. She was afraid that these opposites would place the family in two warring factions. But the patient really had to have somewhere feelings similar both to Anthony and to the nurse-observer. These opposites existed within each individual there and

especially the one who has to make the decision. An ideal situation would be calm enough so that each person could search out these opposite feelings, each within himself. Then there would be less need to find the opposite as negative, destructive, bad--even as the ability to feel guilt within reduces the need to fix blame on someone else.

The second person I will describe is Mrs.Z, a forty-five year old woman, first seen by Dr.G. (her physician and a member of the IDS) after being referred by her physician-cousin. Mrs.Z's husband had died of multiple sclerosis three years before Dr.G. met her. She had a radical mastectomy, radiation treatments, and anti-cancer drugs. Even when Dr. G. first met her, the tumor had spread to the chest wall, and then spread widely throughout her body. After her husband died, she and her three sons moved from her home in another state to a nearby town to live in her sister's home (because Mrs. Z received her medical care in New Haven). Her mother was living at that time in the same house. Altogether living in the house were the G.'s (the patient's sister, the sister's husband, their three children), the mother, the patient, and the patient's three children. This was to be a temporary arrangement until the patient could find a suitable place to live. The family relationships had always been tense. The patient had been estranged from her mother for years, and now was thrust into the same home. The tensions seemed to grow.

Her sister was going to build an extension on her house for her and her three children, but the patient rejected this. Mrs. Z had always been very independent, and especially so since her husband had died. She finally moved into a cooperative apartment. This was better than trying to live in her sister's household where there had been four adults and six children. Mrs. Z's sister ran a particular household where discipline was maintained. The patient, on the other hand, had been indulgent with her children, especially after her husband died. The sister's husband was very hard on the children. According to the sister, the patient's children "hate his guts."

The oldest child, Gary, was eighteen, and had attended three high schools since starting as a freshman. He had considered college for the next year, but was also interested in finding himself. The second child, John, fifteen years old, had one eye with no sight at all (congenital), had grand-mal seizures, and was on anti-convulsive therapy. Steve, thirteen years old, was very close to his mother in a dependent way. The two younger children had "no idea of what was going on with their mother." The oldest had an idea that she was sick, but did not know much more. No one had talked with Mrs. Z's children to tell them what was happening, as the patient did not want them to get involved in her illness or potential dying.

The patient was seen by the nurse-observer several times during clinic visits between November, 1969 and February, 1970. At that time she had to stop work, and was having difficulty

managing household tasks. Dr. G. and the nurse-observer explained the study to her and to her sister and asked if she would like to participate. She agreed.

Responsibility to family by health professionals

The disease was now rapidly progressing. The health professionals viewed the patient as part of a system that included patient, family, and health professionals. The professionals had tremendous difficulty with their feelings of responsibility in the eventual disposition of Mrs. Z's children.

One of the reasons the patient did not discuss her condition and its consequences with her sons was that she felt they had experienced enough of sickness with their father, who had died slowly of multiple sclerosis. Concerned about the children and blocked by the patient's apparent need for denial, a conference was arranged with the physician-cousin, the oldest son of the patient, and Dr. G. The conference's openly stated purpose was to probe to find out more about the family situation. Both the physician-cousin and Mrs. Z's sister were enthusiastic about anything they could do to help the patient. Dr. G. asked the physician-cousin if the patient should be at the first conference. The physician-cousin had mixed feelings, but felt it would be better not to have her present the first time. He said he would be uncomfortable and upset if the patient were there and everyone was talking about such things. Dr. G. said, "We're all upset about it, but maybe this is the sort of thing that we really ought to get involved

in." He agreed, but not for the first conference. The oldest son was told that they were going to discuss his mother and the problem with her illness. The patient was not informed of the conference. Dr. G. thought the patient would be terribly upset if she knew about the conference and wondered if they should swear the members of the conference to silence. Florence Wald felt not. Dr. G. asked, "Do we let the teen-age son take home the message that we spent the afternoon talking about you and what we're going to do after you're dead?"

(Author's comment: The responsibility felt by the health professionals for the patient's children seems really admirable. The decision to exclude the patient was bound to cause complications. The patient was blocking information from reaching the family. The health professionals arranged to go around her without her knowledge. The decision to do so was again based on feelings. But the feelings that were held most important in this system were those of the physician-cousin and also the patient's sister and brother-in-law. They said they would feel uncomfortable if the patient were there. How would the patient ever be told that the conference was held? What would this do to her trust in the health professionals or family?)

What are the patient's responsibilities to her family?

In this system of patient, family, and health professionals, can the patient's responsibilities to her family be defined? If so, how and by whom? If the patient is passive and does not

prepare her family, is she avoiding her responsibility? The health professionals were perplexed and had mixed feelings, but came to the agreement that it must be up to each patient to define his own responsibilities. The health professionals could not do this for the patient. However, the health professionals could ask what was being done. They could also convey this concern to the patient.

The conference

The oldest son was ill and did not attend the first conference. Another conference between Dr. G., his pediatrician, and himself was held a week later. He was relieved to know that the hated and bad uncle would not be at the conference. When told that his mother was very ill, he said he had known she was ill, but had not known how ill. The oldest son had strong views on future plans of placement for himself and his two younger brothers. The bad uncle and aunt were absolutely out of the question. He felt the same way about the possibility of living with his grandmother. This left things somewhat up in the air. The physician-cousin said that he and his wife could make room for Gary in their home, but not for the two younger sons. Since the physician-cousin was going on vacation for ten days, a decision was made to do nothing for the time being. Dr. G. felt he could not discuss the conference with the patient. Then Dr. G., the physician-cousin, and the oldest son made a decision not to tell the two younger sons yet.

There are too many people trying to tell me what to do!

At a clinic visit the patient spontaneously talked to Dr. G. about her family. She said it troubled her that there were too many people telling her what to do. Her mother was very domineering and her sister felt she had all the answers. She felt that she herself was the one who should plan for her children, and she was doing this as best she could. She told of her oldest son who worked all afternoon after school, came home for dinner, and went to meetings afterwards. By the time he was home and finished with his homework, she had, at best, half an hour to talk to him. By that time, she was sleepy. She saw him only on Friday night when he did not work. The patient was still working from 9:00 A.M. to 3:00 P.M., and was saving to have a skiing vacation for a Christmas present for her children. At home she did the laundry and cooking. Her sons did the vacuuming and helped with the heavy things.

(Author's comment: Again, the person in the family given the most information is not only the eldest son but also the one who has the least actual contact with the patient and family. His attempt to carry the burden of bad feelings led to a decision not to tell his two brothers. The nurse-observer at this time said, "I feel very uncomfortable in what we are doing around the patient and not including the patient. I have a lot of inner difficulty with that.")

One mis-step and we may destroy the whole relationship

At a research conference of the IDS, the team members

discussed the issue. Dr. G. was trying to find a way to bring the patient around to talking with her sons. He felt he might "ask her point blank, . . . 'maybe it's time we sat down and talked about your sickness to the children and see what would happen.'" He felt she might say no, but if she said yes, then everyone could bring this in the open. Dr. W. suggested a middle-of-the-road position, saying, "I am curious about what your plans are for discussing your illness with your children," and then see what happened. Dr. G. felt that the patient had not accepted her terminal outlook visibly or verbally. He said, "She faced it inside and can't quite break the little shell. She can't break it to get out and talk about it." The nurse-observer felt Dr. G. should do whatever he felt comfortable doing. She felt the patient had an understanding of Dr. G.'s interest and concern, that Dr. G.'s relationship with the patient was meaningful. The nurse-observer noted about a recent clinic visit: "She (Mrs. Z) came in anxious, almost tearful and most angry and her eyes kind of looked hard, and she really wasn't communicating. After Dr. G. had talked to her, her eyes softened up and she was suddenly able to see again." The nurse-observer said to Dr. G.,

"I don't think you are going to do any harm."

Doctor G.: "This may be part of the problem because if we go into this in the wrong direction, one mis-step and we may destroy all of that."

Nurse-observer: "I don't think you would ever do that."

Dr. W.: "What's that?"

Dr. G.: "The relationships we have got."

And later Dr. G said,

"I would not at any cost, however, want to risk getting her into the situation where she feels she is no longer able to talk to me."

Rev. D.: "That's right. That is true."

Dr. G.: "That is the one thing that we have at risk, and if we destroy that . . . then we have really nothing left."

(Author's comment: This fear was expressed by many of those involved with the patient, especially health professionals. I chose this one example from many. This may partly be a phenomenon of a group doing research, but it also has to do with the dying patient. The feeling of many persons involved was a fear of doing something that would destroy the relationships. I feel this is much more fantasy than reality, but the fear is real. In fact, a few weeks later someone suggested that Mrs. Z might have some of these same fears herself, that somehow speaking with the children, "the dam gets opened and they all are going to be blown apart." However, the data shows over and over again that open discussions and planning have proven to be far less destructive than covert planning and discussions.)

The oldest son

The oldest son was living with the discomfort of knowing about his mother's illness, yet acting as if he did not know. Members of the study wondered how long he could last like that, and felt responsible for putting him in that position.

A few weeks later, Dr. G. received a phone call from the oldest son. He wanted to know what Dr. G. had found when the patient made her clinic visit.

He said he had been talking to his psychology teacher--he is interested in psychology--and he talked to a few other friends about what he should do. Should he sit down and talk with his mother about her illness or shouldn't he? What did they think? And it is very interesting. He reported to me that uniformly they all said, "The best thing to do is for you to talk to your doctor and then talk to your mother, and everybody talk about what is going on." Which I thought was marvelous. I thought, "What are we doing this research for if an eighteen year old kid can go ask a few friends on the periphery, and come up with the same kind of conclusion?"

At a later clinic visit, Dr. G. suggested to the patient that it was about time for her to sit down and talk with her oldest son. She did this, but the oldest son felt that very little had been accomplished, and he was unwilling to talk about her illness. Dr. G. felt that she was willing to see the kind of help she wanted, but was afraid to get it from her children.

Priority set

The patient was deteriorating physically. Emotionally, she was falling apart because her mother, who came into the house to help with some of the housework, caused much aggravation. She exhausted herself just trying to keep her mother and her three sons apart, yet the mother would feel hurt if she had to stop coming to the house. Dr. G. said that he would intervene and call the patient's mother (who was also a patient of Dr. G., and also had breast cancer) and tell her

not to go to her daughter's house in the afternoon. He would make it explicit that this was not helping the patient. Dr. G. said that she would just have to reinforce this, and said the priority was going to be the patient first, the children second, and the mother third. The patient was the person who was going through this at the moment, and her mother was just going to have to put her own feelings aside. The patient seemed very responsive to this type of support.

(Author's comment: Priorities are present in a system this large. They are necessary, but often unstated and inconsistent. This helps to clear up confusion and to direct action and energy of the system toward goals. Here the patient's feelings ranked first.)

System defined as a team

The nurse-observer was at the patient's home daily, giving Mrs. Z injections, changing her dressing, and helping with whatever household chores had to be done. While in the kitchen, the youngest son whispered to the nurse-observer, "Can't you stop my mother from smoking?" Mrs. Z overheard the whispering and asked what her son was saying. Mrs. Wald wrote:

I came back and told her that he said he was worried about the smoking and I said, "You know, Steve, the way this is working right now, your mother's the captain of the team and you notice when she takes the puff of a cigarette she just takes one puff and then she coughs and then she puts it down. She's the person who knows at this point whether or not it's doing her any harm." Then he said, "Yes, but you know, I'm so worried about cancer and all those things." And I said, "Well, I felt the most important thing at this point was for

your mom to get relaxed and to see just how far we could help her along." I said, "I'm not quite sure where we're going to get, but if we all work together as a team and if your mom as the captain tells us what her symptoms are and if you let me be the coach and everybody pulls together, then we have a lot better chance for good results."

(Author's comment: Not only is there an open statement of priorities, but there is also an open statement of the system described as a team. Any new member entering such a system could immediately be oriented. This becomes a tremendously useful tool and guideline for all the day to day events that occur. A system established in this manner enables the patient to make decisions and actively shape her own life. The help is not smothering, restricting, or infantilizing; it is neither too much nor too little, but what the patient wants and needs and asks for.)

Three possibilities

The nurse-observer and Mrs. Z seized the opportunity on a warm sunny day to take a drive into the country, where the nurse-observer was able to talk in depth with the patient.

The nurse-observer reconstructed their conversation:

(Nurse-observer speaking) "I'm worried about what could happen and I can see three alternatives open. One is that you can get better, the other is that you can stay the same, and the third is that you could get worse. And I feel as if we need to know what we're going to do with each of these alternatives." Fortunately, my attention was somewhat taken up in trying to find Ridge Road which does wind around because I'm not that familiar with that territory anymore. I had to keep my eye on the roadside. The scenery was exquisite and there was a lot to keep us both in a calm and good frame of mind although we were dealing, both of us, with an extremely difficult subject. Mrs. Z's next comment was, "I don't

know what's before us, if it's weeks or months or years." I shared with her that I didn't have any better idea that she did, but asked the question "What would happen in the case that you die?" She then explained that she has a will, that her sister has been named guardian of the children, and that her sister has power of attorney so that she can get to her safe deposit box.

Youngest son's concern about his mother's illness

The youngest son was not informed of what his mother's illness was and what this would mean to him and the family. He kept asking questions that showed his concern. He offered suggestions on diagnosis as "I bet I know what's wrong with you. It's your white blood count." Finally Mrs. Z became very edgy and said to Steve, "Now that's enough, I can't talk about it any more now. If you have any more questions, I think you should go and talk with Dr. G." And Steve said, "Yes, that's just what I want to do. I want to go and talk with him." She said, "Fine, that's what Gary's done." The nurse-observer added that she thought Dr. G. would be more than happy to tell him as much as he could. Steve also offered suggestions on what to do to get better. For example, he told the nurse-observer, "I wish she'd get married again. I noticed that women who are married aren't as sick, like Aunt Claire and Aunt Rose."

In an exchange later with the nurse-observer, Steve first said that he found his mother's sickness a pain in the ass, and then excused himself for using such language. The nurse-observer said she knew how hard it was for him, and that he could use that kind of term. He said he was scared, and the nurse-observer asked what he was scared about. He was concerned about

what might happen if his mother did not get better. He was afraid he would have to live with his aunt and uncle again, and described that as awful. He also felt that it was not fair that his father had been sick and now his mother was sick. On another occasion he said to Mrs. Wald, "She's just got to get better. She's my whole life." The nurse-observer said, "She's not your whole life. You have your life even without her." And on yet another occasion, when he was feeling the impact of his mother's illness even more, he said "If anything happens to her, I'll be ruined." The nurse-observer replied, "You're much too strong to be ruined. If anything happens, you're going to hurt a lot, but you're not going to be ruined."

(Author's comment: It may have been harder for the youngest son to accept reality, but the members of this system also made it harder for him. He was one of the last to know what was really happening. Yet, from his constant questioning, one can feel that he really wanted to know, and really needed to work through what this meant to him. This takes time, and also seemed to require another person to whom he could speak honestly and openly about his feelings.)¹

Confrontation between the nurse-observer and Gary over secret information

Gary had been staying away from the house even in early

¹The night his mother died, he said he had known she was going to die since last December.

evening. Mrs. Z was really upset and told him directly, "I really need you here. I need to know that someone is in the house." From the nurse-observer's notes:

The nurse-observer said, "Gary, we really miss you around here." I felt angry at him and I slapped him on the knee, sort of half affection but half I'd really like to slug you--. This was what I was feeling. I said, "Really, Gary, we've been having a lot of meaningful conversations and we need you in on them." He said, "Can I talk to you alone?" I said, "But we're talking in the open in the family." He said, "I want to talk to you alone." I asked Mrs. Z's permission and she said, "Okay." He took me upstairs and then whispered, "Does everybody know what's happening?" I said, "Yes." He said, "But Dr. G. and I agreed that we wouldn't tell the younger children." I said, "The problem is that your mother said she'd answer any questions that the children asked and they're asking all these very specific questions about your mother's illness and about what the outcome is going to be. They have eyes and ears and there isn't any way you can stop this. I think the more that we do behind one another's backs, the more difficult the situation is going to be. That's why I wasn't very keen about coming upstairs with you and discussing this, because I feel it should be done in front of your mother."

(Author's comment: This could be described as a confrontation or dialogue between sharing and non-sharing. The nurse-observer had learned at this point how to handle such a situation when it arose in this family. What is more important, this can be learned. Something can be much easier to learn after another person has been through it before. The nurse-observer had been this other person from whom I have learned. The day-to-day guide that can be learned from this example might be stated: If an open sharing system is the goal, then an open confrontation with non-sharing will help to reach this goal in many instances.)

"It's awful, but I just feel calm and cold."

Mrs. Z was expressing her concern about what was to happen to her second son John, and whether or not to send him to a prep school, as had been suggested by another health professional. As she talked, tears were streaming down her face. The nurse-observer was changing the bandage on her rather extensive chest wound. Later, as Mrs. Z was getting dressed,

we again began to talk about the children. I said, "In any event, I want you to be reassured that Dr. G., Dr. S. (the physician-cousin), and I will always be available to help the children, no matter what happens. If you become better, the same, or worse." This seemed to give her great relief, and she commented, "You must have a wonderful family to let you do this kind of thing." I then explained to her my feelings on the commitment of my own family and it gave us a better and more realistic understanding of the way life is--that it was important for the children to know that sometimes they had to give some things up.

Later, Mrs. Z, John, and the nurse-observer were in the same room; and Mrs. Wald writes:

I took the opening by saying that his mom and I were upstairs and were talking about you and wondering what's going through your head. He said, "About what?" And I said, "Either about your mother's illness or how you feel because you're so quiet." His response was, "I'd be a pretty sad character if I couldn't tell you." His mother and I both were attending to what he said. He said, "I feel pessimistic, over-pessimistic." My comment to this was, "Well, I don't know whether it's over-pessimistic or over realistic, maybe, in the face of the very difficult circumstances of your mother's illness, your dad's death, all these things. It's perhaps realistic. Then he said, "It's awful, but I just feel calm and cold." In the midst of this Steve suddenly burst in the backdoor with a friend and introduced him to both of us. The friend was the one who was going to help him cleaning up the cellar. Mrs. Z took the initiative at this point to say to John--when the two boys had disappeared down the stairs--"Well, let's go back to what we were talking about an instant ago."

Again John said, "I just feel--I don't have any feelings about it. Maybe this is awful." Then I commented that it was important for him to know that Dr. G., Dr. S., and I are available and probably many other people that you can think of. "When you need help, you can come and get it." Then the conversation closed.

(Author's comment: Examples of events being done the right way are much harder to comment on than when mistakes are made. Comments are almost senseless compared to the experience. All I would like to say is, "Look, this is possible. This is really beautiful. Here one persons is really 'with' another person. Here there is no hiding behind procedure, uniform, or routine orders. This is what medicine should be and can be.")

Decision of hospitalization--Gary's feeling acceptance

Mrs. Z's condition had deteriorated; she suffered an increased difficulty in walking and an increased breathlessness. The three sons began to show fear in being with her. Steve, the youngest, did not want to stay in the house alone with her. John, the middle son, had been concerned enough to speak to his uncle, who really leveled with him and told him that his (John's) prediction that his mother would live for only a few more years was an overestimation. He said it would more closely be only a matter of months at best. Gary was also concerned. Dr. G., after receiving this information from Mrs. Wald, called and told Mrs. Z that he felt she should come into the hospital. He asked her to think about this and let him know by calling him back that afternoon. He felt that she

was not receiving as much help as she should at this point at home, and that the situation was very hard on the children. Dr. G. then spoke to Gary and made it explicit to him that it would only be a matter of days to weeks before his mother would die.

The nurse-observer reminded Mrs. Z's sister that she still considered Mrs. Z the captain of the team, and that Mrs. Wald felt responsible to relating to Mrs. Z in this manner. The sister accepted this.

Within a matter of days, Mrs. Z's condition had deteriorated to the extent that, in an attempt to get to the bathroom, she weaved back and forth. Gary and the nurse-observer came to her assistance. By the time she reached the bathroom, she collapsed onto the toilet seat. She became extremely annoyed with herself for not being able to manage on her own. She said, "It's like trying to move a ten ton Mack truck around." After she had rested, the nurse-observer asked Mrs. Z if she would like her to call Dr. G. She said she would like to speak to him if someone would get him on the phone for her. In speaking with Dr. G. on the phone, she said that she was very satisfied with going into the hospital.

Soon afterwards, Gary and the nurse-observer were alone together. Gary was very confused. He said that while he had been able to accept his mother's death intellectually before, with her now going into the hospital, it was beginning to hit him emotionally. Then he cried. The nurse-observer writes,

"I wanted to put my arms around him, but at first resisted, because I thought that he might not like it. But when he continued to cry, I could no longer resist and he permitted me to hold him in my arms and sway him back and forth and comfort him."

Later, as Gary was helping the nurse-observer to get her coat on to leave, he again burst into tears. He talked about how he had been making such a big thing of being independent but how much he really needed to depend on someone else at times. The nurse-observer asked him who he could rely on. He mentioned a few persons. But again he burst into tears. The nurse-observer said, "You know, Gary, it's now about 11:00 P.M. and really I could stay here just as easily and I could go down and lie on Steve's bed. I just hate to leave you alone." (His brothers were visiting relatives in another state.) He seemed extremely relieved at this suggestion. The nurse-observer said, "'Let's ask your mom how she feels about it. If she is in agreement, I can just call up my husband and stay over,' because we had already agreed that I would be back at 9:45 the following morning so I could help with Steve." Both the patient and his mother felt that it would be good if the nurse-observer stayed.

After Mrs. Z arrived at the hospital she told Gary that she was concerned that he had used up so much of his time over her and had not yet applied to college for the next year. She

said she would feel more comfortable if he were going to school next year. Mrs. Z then concretely suggested that Gary go to Wesleyan. Gary listened, crying, and reassured his mother that not her illness but his need to find himself was taking up his time. Gary wanted to take a year off to do this. Mrs. Z said she would feel more comfortable if he would first finish one year of college and then take off a year of independent study. Gary left with the nurse-observer and fought back his tears until they reached her office. The nurse-observer offered to talk for a few minutes. He said about his encounter with his mother, "I just don't know what to do. It just made me feel so guilty." The nurse-observer explained that while this gave his mother peace of mind to tell him what was disturbing her, what Gary actually did with that information was up to him. The nurse-observer said, "Surely, you can't be too deeply influenced just because this is a wish on her death-bed." He said he realized that he shouldn't be coerced into anything, but that he felt this all coming at him so fast that it was difficult for him to maintain his balance. Again he broke into deep sobs. The nurse observer writes, "I held him tightly in my arms while he cried unabashedly." She also suggested that he try not to make a decision too fast, as everybody was under a tremendous amount of tension. She also suggested that he could make his mother more comfortable by at least going to the admission office and looking at colleges; however, this did not have to commit him to anything. He agreed.

(Author's comment: This is an example of a sharing system.

Every member shared information about Mrs. Z's deteriorating health, expected hospitalization, and expected death. Everyone shared fears and concerns. While others participated in helping Mrs. Z to make a decision, the final decision was left to her. She entered the hospital when she felt she needed this--not because the family or the physician felt this was necessary.

Gary was able to share his feelings with the nurse-observer. He said that, although he had made such a big deal of being independent, at times he really needed someone to depend upon. But this happened when one person really needed and asked for another person. To reach out and hold a person who really needs and wants to be held is not making that person dependent. Rather, this is really "being with" another.

Mrs. Z also was able to share her feelings of discomfort at not having completed her tasks until she saw that Gary was settled in college for the next year. She even made a very concrete suggestion. Later, the nurse-observer's intervention was very effective. Gary would have to be the "captain" of his own life, but he could listen to his mother and at least investigate his mother's suggestions.)

Nursing home decision

The patient reached the point where she was well enough not to require hospitalization, but not well enough to be home without round-the-clock nursing help. She did not like this

idea but said she would talk this over with her sister. When she saw the nurse-observer, tears were in her eyes and she said, "Do you know what they told me this morning?" The nurse-observer asked her what she was talking about, and she began to weep openly and said, "They want me to go to a nursing home." Later, after asking the nurse-observer to describe the nursing home, she interrupted, sobbing again, "Never in my wildest dreams did I expect anything like this. How can I face my children? What will they do? I never expected this. It's like Don revisited." (Don was her husband, whose lingering disease caused multiple hospitalizations in nursing homes.) The nurse-observer said to her, "But we were talking only yesterday about the possibility of your being able to accept the fact that you might stay the same, get better, or get worse." She said, "Oh, but with a little bit of luck, I thought I could make it." The nurse-observer then writes, "She then rephrased some of these things, weeping, and she held out her two hands to me. I held them, and I kissed her head and held her head between my hands and rocked her back and forth. Then she began to become more composed." The nurse-observer then said, "Maybe it's a little like with Gary when you went to the hospital. He said he had appreciated it intellectually, what might happen, but until you really went back to the hospital, he didn't make it emotionally. That was why I stayed with him that night." She nodded her head in agreement.

When Mrs. Z's sister came in, the nurse-observer brought her up to date with the patient's permission to do so. The patient then turned to her sister and asked what would happen to her children. Her sister responded, "As long as my children have a mother, your children have a mother." She said this twice to Mrs. Z.

After this, when Mrs. Z felt the burden of making the decision was too great for her, she said that her sister had felt that one person should make the decision and not have a lot of people telling her what to do. Mrs. Z then said that her sister knew what she (Mrs. Z) could do and her sister would figure it out. She added that if her sister needed help, she could always get help from others. Some days later the patient, looking more relaxed, offered that she was looking forward to transfer to the nursing home. She had decided she could not go to her sister's home, because she would not feel comfortable there. She did ask to see pictures of this private nursing home and meet the owner before a final decision was made. She also felt somewhat relieved that Gary had been accepted in college for the coming year.

Later Steve said to the nurse-observer that his grandmother had said she was displeased with the decision for Mrs. Z to go to a nursing home. Steve said that maybe he should not tell that to anyone because his grandmother had said this only to him. The nurse-observer cautioned everyone against

getting into a "closed system of awareness." She did not use these words in her conversation, but did in her notes. Rather, she talked about not being completely honest with each other, and how this might cause problems. He agreed.

(Author's comment: When the patient could not decide on her own, she was allowed to designate the person who could decide for her. She chose the person she felt would know her needs. The nurse-observer had again made it safe for another person to express their worst fears and feelings. Each time this had freed a person to move on, Again the nurse-observer cautioned against "a closed system of awareness.")

Sharing without thoughts about the other person's feelings

When Mrs. Z had first arrived for admission to the hospital, the intern had spoken to Mrs. Z's sister. He asked questions that disturbed her terribly, such as "whether or not the children should be present when her sister was dying," and "did she and/or the children wish to see the body before anything was done with it," and a few other questions that she could not remember. She said this made her think of the end in harsh and gory terms. She said, "How awful! I don't know what kind of a doctor he is!" The nurse-observer replied, "He did seem to have a different approach or manner than most of the doctors, and the questions did sound upsetting."

(Author's comment:: Not all sharing is beneficial, but it may be more the way it is done that what is shared. The intern had no relationship with the sister and did not seem to

into account the sister's feelings.)

The nursing home

The last page of raw data was written by the nurse-observer on May 12, 1970. She writes that Mrs. Z felt there was too much company. Mrs. Z said, "It's not necessary. There's nothing to talk about." She said that she really only wanted to see her sister. She said, "It doesn't even bother me to see the boys daily. I think about them, but they're a strain on me." She became flushed and tearful and said that she was afraid she lacked mothering instincts. She said she knew they were managing well, but felt guilty that she did not think about them much or worry about them.

The nurse-observer then writes:

I asked her how she thinks this home compared with her returning to her apartment. She said it took so much off her mind, so she could put all her energy into gaining some strength. She said she did not have to think about the food stock, the menu, the fact that lunch time was upon her. We were watching the birds and the bees. I commented that there seemed to be a natural rock in the form of a low bird bath that a robin was splashing in. We both enjoyed the scene. She said, "There's always something different to see when you look out." This is so true. There is no orderly rigid plan to the yard--no main focal point, but many interesting areas. She is reading again. She is half through a mystery in paperback. She says that it's easy reading. She listens to her new radio with interest. She said that she would never go into a convalescent home. Last Friday, as sick as she was, she would have gone home. She explained the experiences of having her husband in a poorly run one. That, besides poor help, people were dying all the time and the old people were so pathetic. She felt this home was ideal.

Mrs. Z seemed to gain new strength at this home. She was able to walk about freely, her appetite was regained, and her

dyspnea subsided. She had very little pain which was controlled with Talwin. On the evening of May 30, just after supper, she suddenly had marked shortness of breath and was hospitalized. She was very uncomfortable for about twenty-four hours, chiefly because of the breathing problem. She died at 7:00 P.M. May 31. Her sister was by her bedside and holding her hand most of these twenty-four hours. Before she died she had said that these weeks at the nursing home were like the vacation she had always dreamed of, but had never had time to take in her life. She felt peaceful and dreamed of fishing. Coincidentally, she died and was buried on the anniversary of her husband's death.

(Author's comment: If the extent of sharing can be determined by the patient, then she can meet her own needs to be more alone, to begin what Dr. Elizabeth Kubler-Ross (1969) has described as separation. Mrs. Z was able to live her final days in the manner that she chose, to sing her own song.)

CHAPTER V

SUMMARY AND CONCLUSIONS

Some concluding remarks

I feel that we in medicine need to examine how we involve ourselves with other human beings. People come to a doctor because they feel bad. A certain level of anxiety seems to be reached that motivates a person to seek help (Duff and Hollingshead, 1968). How does the health profession react to that anxiety? Kenniston's statements (1968) say that those who enter the health professions, especially doctors, have as a way of coping with anxiety a desire to counter, master, and overcome this by changing the environment. Also, bad feelings are intellectualized and an attempt is made to do something action oriented. With the ever increasing number of technical appliances available, the health profession has relied on these increasingly. Not only have the health professionals applied more and more techniques, procedures, and equipment to a human being with an illness, but this question is always there: Is the doctor not legally responsible to use all means at his disposal for the patient's benefit? Not so long ago in some states, the court system was used to force individuals to take medicine prescribed by

a doctor as necessary. If a patient did not take his medicine and his life were in jeopardy, the court construed this as committing suicide. In the hospital, not doing everything possible in terms of treatments and instruments, has also been construed, by some, as killing a patient.

What has happened in this process has been a movement further and further away from meeting the felt needs and anxieties of the patient and more and more toward meeting the bodily needs of the dying and the needs and anxieties of the health professionals. The best way to handle the patient's anxiety might not be to do something to him to change his internal or external environment. Especially if a patient is terminal, the best way to help him might be to help increase the quality of his life as he sees it and with regard to not damaging or depriving others unfairly, rather than to increase the quantity of his life. A procedure, while lengthening an individual's life, may make him miserable, confine him to a hospital, and cut him off from much of the meaningful and joyful parts of his life. As long as the doctor making the treatment decision places his own anxiety above the patient's, in terms of doing all that is possible, then the doctor is being treated as much as the patient. Also, I believe too much emphasis is placed on the scientific aspects of medicine and too little importance is given to the reason for its being, an instrument of humanitarian aims to bring relief to the anxiety and suffering of the patients and

strength to the patients' recuperative interests and powers.

Today when we are witnessing around the world and in our nation an increasing demand that persons share power, the old doctor-patient relationship where the patient is subordinate in power and decision making will also be challenged. The patient will ask more and more to share in the plans and decisions. It is inconsistent that a person who grows through life should be offered invitations to infantilization rather than opportunities to be active in his own behalf. Today the person who wants medical care has little choice other than to participate in this system: he has no other place to turn for help. To help another human being is the satisfying part of medicine. But we must be careful how we help. We must be certain we are really helping this person.

We need to develop a system with no conflict in meeting the multiple aims of (1) do no harm; (2) help the patient to help himself; (3) help a student in training to learn more about being a useful, humane doctor; and (4) advance our knowledge about human beings.

To become humanly involved with another person in distress is to build a bond of human relationship and responsibility. That bond makes us sensitive to the other person's human needs, makes us want to know the consequences of our interventions, makes us want to follow what happens with the

life of the other person. That bond is an essential ingredient of sound medical care, regardless of the health condition. And then, when needed and in keeping with the dignity and humanity of the patient, the additional medical knowledge and skills should be applied.

The moral issues that seem to have been long set aside by medicine can be answered. The escalation of technical apparatus in medicine does not mean that everything possible must be done in terms of technical procedures to prolong life. Any time there is a general rule, there are bound to be exceptions. The necessary instruments to insure human morality exist--not as external apparatus--but as internal tools. First, there must be an acceptance of medicine with a base in a relationship of equal to equal; second, health professionals must allow the final decisions to be in the hands of the receiver of health services; third, health care must be used to promote the potential "becoming" of a person; fourth, feelings must be given equal weight with intellect.

Medicine, wherever it is applied, is instantly part of a system of individuals--health givers and health receivers. A health professional would not operate on a patient's body without permission, just so we must obtain permission when entering the patient's and family's feelings and personal life. We are so fearsome of legal permission that we seem to have forgotten the human implications behind such permission--that this is the way one human being relates to another.

Just as a surgeon would answer questions and fears of a patient who needed an operation, so too we must stay with a patient and help him answer questions and fears about his dying and the implications this has for him and his family. If health professionals succeed in doing this, the system will more closely approximate a sharing system as the model for health care. In this model information, feelings, decisions, and tasks are shared by all those involved. Priorities are set, as they must be when more than one person is involved, as to whose feelings and decisions will determine what to do when there is conflict or disagreement.

If priorities are set where the patient's feelings and decisions come first, then medicine's involvement with the patient may be more appropriate or effective for that patient. Just because we in medicine seem strongly identified with certain types of coping mechanisms for anxiety, the patient may not have the same need to cope the way we do. This "scientific" way of coping, by resorting to action and intellect, is part of a national coping method in the United States where we have long felt that we have the resources and tools to conquer any problem. But in the end, dying seems best to be conquered by acceptance.

In our times when death is often not accepted, the feelings of guilt associated with death are not accepted either. This probably plays a significant factor in mental illness in our country, the secret holding of an unacceptable guilt. In

a sharing system of health care, each individual can realize that he is not alone in having these terrible feelings. Perhaps each person can accept these feelings as part of a natural phenomenon associated with death.

Summary: A dialogue between Sharing and Non-sharing, with other characters entering

NS: Non-sharing

S: Sharing

NS: Our resources are so limited. There are too few health professionals, too few hospital beds, too little money, too little time. What we need is more of the same. Look at polio. If we had directed money toward only patient care, perhaps there would now be millions more needing treatment. Resources directed toward research and medicine as a science help more persons in the end than medicine that directs its resources to immediate care of the patient.

S: Aha! Now I have you! In other words, you believe in preventive medicine.

NS: Yes! Yes! I believe in preventive medicine.

S: But then you should believe in preventive medicine as far as mental health goes, too.

NS: Sure, I even worked with a group at the National Institute of Mental Health. Some day we will have a pill to cure schizophrenia.

S: What if I told you that medicine today plays a significant factor in causing rather than preventing mental illness.

NS: Now you are really going too far. You must be crazy. Some day we will have a pill for you!

S: You can at least be polite enough to listen. After all, I listened to you.

NS: Go ahead, but be quick, for I have matters of consequence that await me.

S: The way medical resources are set up today, the result is sporadic, fragmented care. I have to take my liver to

one guy and my kidney to another. I wait for appointments. I sit long hours in unfriendly waiting rooms. I am then rushed in to some small room, sometimes without anyone even saying hello or asking how I feel or even wanting to know why I came. Instead, someone says something like "Take off your clothes! The doctor will be here in a minute or two or more." When he comes, he pokes me and jabs me, enters my body with strange instruments, and takes specimens from my blood and urine and other embarrassing places. Often the doctor spends hours talking to my kidney. He often never says hello to me. Now I am sure my kidney likes him. He falls for all those fancy gadgets and is often neglected by most persons. But I never get to know the doctor; only my kidney does.

NS: What is your point! Be specific! Communicate clearly!
Don't waste my time!

S: The point is that I as a person am neglected by the doctor. In terminal illness, the doctor continues to relate to organs and neglects the person. Persons in the family feel tremendous guilt. I imagine the persons on the staff also feel such guilt. The way it is handled is by doing some more procedures. I am sure this is a significant factor in mental illness in our country; unresolved, unaccepted guilt carried for years or a life time by some. Death is seen as the enemy.

Death: Did someone mention my name?

NS: Oh, this is terrible! I feel so anxious! Quick, do something! Death is here!

Death: Relax, I am always here.

NS: Then I don't want to be here. I am going back to my laboratory.

Death: I am in your laboratory also.

NS: This is even more terrible than I imagined. Here, let me take one of these tranquilizers.

Death: Oh no, not that again.

NS: La La La. Life is forever. Who's afraid of the big black death.

Death: I do not ask you to fear me.

NS: Ahhhhhhh! Gulp! You are still here. I am going to take more tranquilizers!

Death: Now look at him. He has taken so many tranquilizers that he has passed out and is slumped on the floor. I don't mean to scare people so much. I just want to be accepted like anyone else. But this is a beautiful example of what happens when I am not accepted. A person who takes so many tranquilizers to get away from me cannot be living, rather he is like our friend NS here, passed out on the floor.

S: Yes, yes. I think I understand. He is so afraid of you that he runs away from life, or he uses up all his energy in defending himself against you and has none left to live.

Death: That is right. NS spends all his day working in a laboratory to find ways to kill me. That is such a joke. When he uses all his energy in such a manner, he does not realize that his life is more entwined with death than if he just accepted me. I would then visit him once in a while only to establish a relationship. That is only what I want, a real relationship. Instead, I am the enemy. He is the conquerer. That immediately places us at battle.

Patient: I am the one that really suffers. The battle is fought on my body. There is no Geneva code or anything to respect my feelings.

NS: (Regaining consciousness) Another person! Who's that! Who's that!

Patient: I am a patient.

NS: What the heck is a patient doing here? He has no right here. Someone get him out of here!

S: Why don't you talk to him directly.

NS: Talk to him directly? Can't he hear me? Doesn't he realize how I feel? Doesn't he know how valuable my time is? I have matters of consequence!

S: What do you mean, your feelings? What are your feelings?

NS: None of your business.

S: Then the patient stays, unless you can give me a good reason why he should not be here.

NS: He won't be able to understand the language we use.

S: Can't you explain what you are talking about so that he can understand?

NS: That takes time. I have matters of consequence.

S: What are you going to do with your time that is more important than speaking with another person, especially one you are treating?

NS: There is the whole problem of death to conquer.

Death: Really!

NS: My tranquilizers! Where are my tranquilizers?!

Death: Don't you realize that when you take a tranquilizer you are killing your feelings? You do the killing, not me.

NS: I feel so terrible. I am so anxious. I have always been so afraid of you, Death.

S: Now how do you feel that you got that out and said it?

NS: Still terrible, but my legs do not shake quite so much.

Feelings: At last someone has freed me! I love you for doing that.

NS: Really. Do you know you are really quite beautiful. Why don't I have more patients like you?

Feelings: I enter the door with each patient, but then I am neglected. When I am neglected, I get frightened. Sometimes I feel that no one knows I am alive. When that happens, I jab the body here and here.

Body: Ouch!

NS: Look! A symptom! Now we have something to treat!

Feelings: You have done it again. You already spend enough time with the body. How about me. Can't I get to know you too?

NS: Quiet! I am busy! I am treating a symptom. Now Body, take these pills and you will feel better fast.

Body: Thanks, NS, but do I swallow these or shove them up my rectum?

NS: Oh, you mean you don't know that? Well, take one of these red ones by mouth every three hours. Then take a striped one every twelve hours. Take two teaspoonsful of this liquid once a day.

Body: What is the liquid for?

NS: That is to treat any possible side effect of the other two drugs.

Feelings: I am so anxious. Look at all those things I have to regulate my life around. I will be so busy that I won't be able to walk in the woods or just live freely.

NS: Anxiety. Another symptom! Here, Body, take these pills. These will make you feel more relaxed. I use them myself.

Feelings: No, no. I only poked the body and made him hurt so that you would say hello to me. Instead, you are going to kill me with that tranquilizer again.

Death: If you are going to use me, I demand that you do this consciously. I demand to be recognized. I demand a relationship.

Feelings: I demand a relationship also. If you do not relate to me, I will become bored. What is worse, I will get angry and spiteful. I will make the patient not like you or respect your crummy medicine. If you had just said hello to me, I would not have poked the Body so hard and you wouldn't have put all that energy into a bodily symptom. That bodily symptom was angry and frightened me poking the Body. Body said ouch because you would not listen to my ouch. In fact, when I came into the room you neglected me entirely.

NS: You must want a psychiatrist. Wait a minute.

Feelings: Ha! Many of them are as bad as you in having so little understanding of me. At least I have been talking to you. Maybe I have already established a little bit of a relationship.

Author: Could I introduce some aspects of the system that I would like you to discuss with Sharing and Non-sharing? I wish the rest of you would please stay also. Feelings, I find you beautiful and wise. Death, you are interesting and not quite as terrifying as I would have imagined. The patient should stay here too. Body, now I can see that you have a better relationship with feelings than many of the rest of us. I am finding this quite fascinating just listening, but would like to help direct

the conversation so that we can answer questions the reader may have. For one thing, I am not sure that I really heard a reply to NS's statement of the limitation of our resources.

S: More technical intervention and professionals in the health field is not the only answer. I am not against there being more, but I am appalled at what is not used. A person often needs another person who is not necessarily a health professional. Community workers can be trained. I have heard of some programs in hospitals where aides have been trained from the community within a matter of six weeks. There are family members. Instead of every task being performed by a health professional, why not train the family members? The health professionals' role would be one of teaching and enabling the family to do the care of the patient where he could not do this for himself. The patient would not be so isolated from the persons he loves. Also, the family members then would not stand around and feel helpless.

NS: Who is to be responsible? What if something happens? Who will be blamed?

S: That is an affliction of our present care system. We are always concerned about who will be blamed. We always think in terms of bodily injury. What about responsibility to feelings?

Feelings: I feel we are going to be real friends. (Blush)

NS: Who will be blamed? What about all the law suits for malpractice?

S: If each person were regarded as a responsible person, there would be no need for fixing blame. If a person were respected enough to make his own decisions, then he would be responsible to himself. Especially in terminal illness, where everyone feels guilt. Here the fixing of blame can be very dangerous. If it is necessary for one person to be blamed, rather than everyone sharing that they have such feelings, then that person can be badly hurt for the rest of his life carrying the burden of the blame. Much of our health care system is set up so that no one gets blamed. There are often many different individuals caring for a patient doing what is routine and acceptable legally.

NS: There have to be rules and routines!

S: I see only that there are persons. Why are there routines?

NS: Why, why, then no one would know what to do! I would be very anxious. I may take another tranquilizer.

S: That is what I am saying. The system is set up to cope with and contain anxiety.

NS: How shall anyone know what to do?

S: Did you ever think of asking the patient?

NS: He doesn't know anything. I don't want to make him anxious. It would take too much time.

Patient: That is why I am anxious. I don't know what is happening. No one speaks with me. I am afraid of what the doctor is going to do next. Sometimes they don't even tell me anything and the next thing I know someone is shooting barium up my rectum.

NS: Really you are anxious because you don't know.

Patient: Yes, and I would like to be in on the decisions also. I am so anxious just sitting around and not knowing what someone else has decided for me.

NS: Now that I know you are anxious, I feel bad. We should do something about this.

S: You don't have to do, just share.

NS: (Whispering) But I can't let him know about Death.

Death: Doesn't anyone want to know me? Why must you constantly deny my existence?

Patient: I have always known that you were there.

NS: Let's not talk about it.

Death: Why do you suppose he is so afraid of me?

Patient: I suppose he will feel that he has failed if he has not conquered you.

Death: I guess you're right.

Patient: Well, not everyone even in my own family accepts your existence. Together with the doctors they have planned one treatment after another for me.

Feelings: I am furious. Usually the same persons who don't

recognize Death don't recognize my new friend Sharing. Body! Body! Body! That's all I hear. I have even seen doctors keep pin-up pictures of bodies in their offices. And they are always looking at pictures of bodies in their books. Man, they are real body fiends!

Author: I find what you say funny yet true. I like the way you express yourself, Feelings. Now let me see if I can sum some of these things up. Nonsharing cites the limitation of resources (health professionals, hospital beds, money, time), legal responsibility, remaining "professional" (that is, not being emotionally involved), the doctor's right to decide, shielding patients and families from what the doctor thinks might be hurtful. Sharing answers that as long as there are human beings, there are human resources; that if each individual were regarded as mature, and feelings such as guilt were shared, there would be no need to fix blame; that sharing feelings and being involved emotionally are necessary to really meet the needs and wants of the health receiver; that information withheld leads to more pain in the long-run and certainly poorer planning, not only for the patient but for the family as well; that the limits of how much to share can also be obtained from the patient, who will set limits if he is asked.

A few day-to-day guides for a sharing system

The following are a few day-to-day guides that might orient a person in establishing a sharing health system and understanding what is happening in the system at a certain point in time. There can be no general rules where human beings are involved. My conclusions are in the form of questions which, if considered in giving health care, may be helpful day-to-day guides. If they were to be used as strict rules or laws, then they would become one more routine, standard procedure that has already dehumanized much of medical care.

1. Information

A. Who has health care information?

B. Who determines who receives and who does not receive information, and when is information to be shared?

C. How was this person chosen? Is this person the patient, family, or health professional?

D. Is this health care system treating a patient expected to live, or a dying patient?

E. Is there any explicit way that information can be shared?

2. Feelings

A. What feeling is being expressed by the patient, by the family members, by the health professionals? Are everyone's feelings known, especially the patient's?

B. What information can be gathered around that feeling?

C. Whose feelings are being responded to--the patient's, the family's, the health professional's? Is the system acting in such a way that one member's feelings are given a higher priority than other members? If so, is this the patient's feelings? If not, then whose feelings are most important? How was this decided?

3. Decisions

A. Who are the members in the particular system? How many of these members have part in the decision making process? How many are allowed to offer suggestions? How many actually make decisions?

B. Who makes decisions? Has this been decided upon openly? Are all members consciously aware of the decision making process? If someone other than the patient makes decisions, how was he chosen?

C. Whose feelings have the strongest influence on the final decision?

4. Tasks

A. What are the tasks in patient care. Are there any tasks in family care?

B. Who is the task being done for? Is the task meeting the needs of the health giver or the health receiver? Is the task meeting the feeling needs or the bodily needs of this patient?

C. Who does the tasks? Can any be learned by the patient

or family? Is there something so technical that the family would be alarmed doing this without help from a health professional? If the family is allowed to share, are the family members allowed to set the limits of what they feel they are capable of doing?

APPENDIX

APPENDIX I

MR. X'S DISCHARGE SUMMARY FROM YALE-NEW HAVEN HOSPITAL

Admitted 11/25/68

Discharged 2/18/69

This was the first Yale-New Haven Hospital Medical Center admission for this 60 year-old white male Italian immigrant construction worker who entered for elective evaluation of right lower quadrant pain. The patient had acute rheumatic fever at age 13 and in 1956 at the age of 48 the patient was first hospitalized in Italy for a "run down condition" which probably represented the first time he became symptomatic from his heart disease. Shortly thereafter he came to this country where he has been under constant medical care for his cardiac disease manifest by congestive heart failure which was controlled by digitalis and diuretics and complicated frequently by digitalis toxicity. Beginning in August 1963 the patient began to experience epigastric and right lower quadrant pain for which he was hospitalized several times with no explanation forthcoming from extensive studies conducted at another hospital. Because of this pain, the patient was admitted to this hospital for further evaluation.

Physical examination on admission was unremarkable except for the findings relative to the cardiovascular system. Blood pressure 110/60, pulse varied from 52 to 74 per minute. Respirations 18 and unlabored. Temperature 100.4° rectally. There was no jugular venous distension and no cannon waves present in the neck. The chest was clear to percussion and auscultation with only a few fine deep inspiratory rales at the right base. The PMI was outside the MCL in the 5th left intercostal space. There was a left ventricular lift. S1 variable; S2 indefinite with a Grade II/VI diastolic decrescendo murmur along the left sternal border, and a Grade II/VI systolic murmur at the apex. The abdomen was soft, flat and nontender with normal bowel sounds. There were no masses or organomegaly.

Laboratory data on admission: Hematocrit 40%; white blood count 9,000 with normal differential. Urinalysis showed trace albumin with no pyuria. EKG showed complete

AV block alternating with first degree heart block, normal axis, deep Q waves in Leads 3, AVF and V5 through V6 were noted. BUN 25, glucose 162 mg%. Electrolytes: sodium 143, potassium 2.9, chloride 97; CO₂ 28.9. Liver function tests normal with SGOT 33. Amylase less than 200.

Hospital course: On admission the patient was felt to be digitalis toxic. In view of serum potassium 2.9 mEq/liter, the patient was treated by discontinuing his digitalis and vigorous potassium replacement parenterally. On this therapy his arrhythmia gradually resolved and his EKG returned to normal sinus rhythm with first degree heart block, showing signs of left ventricular hypertrophy. With resolution of the cardiac arrhythmia, evaluation of his abdominal pain then proceeded. On November 29, 1968, the patient had a barium enema examination which showed no specific abnormalities. Stool benzidine had been traced on admission and increased to 4+ on November 27. Benzidine positivity continued on the 29th of November and throughout that evening and the next morning the patient continued to experience considerable abdominal pain. On the morning of November 30 the patient presented with all the symptoms and signs of an acute abdomen and was taken to surgery where he was found to have infarcted his intestines from the level of the third duodenum to the proximal transverse colon. Accordingly the fourth duodenum, entire jejunum and ileum as well as the ascending colon and hepatic flexure were removed. The duodenum was anastomosed to the mid transverse colon in an end-to-side manner and a vagotomy and pyloroplasty as well as gastrostomy performed. The patient was hypotensive during the initial stages of surgery and anuric with low venous pressure which responded to parenteral fluids and blood replacement. The patient's immediate post-operative course was essentially uncomplicated. However in view of slight elevation of the serum transaminase post-operatively in conjunction with non-specific ST-T wave changes on serial EKG's, it was felt that the patient may have sustained a myocardial infarction during the operative period. The patient also ran a low grade temperature for approximately 3 weeks post-operatively but serial blood cultures as well as cultures of other bodily fluids and orifices were all negative. This temperature finally resolved spontaneously and no antibiotic therapy was given. On December 30 the patient, having been on digoxin since surgery, again showed signs of digitalis toxicity manifest by a coronary sinus rhythm with first degree AV block and his digoxin was discontinued and was not subsequently reinstated. On January 2, 1969, the patient was transferred to the Clinical Research

Center. During the course of the next six weeks until the present time repeated attempts at discontinuing the patient's intravenous fluids and maintenance of the patient on oral alimentation were unsuccessful. The basic constituent of his diet has been a formula containing fat in the form of medium-chain triglycerides, carbohydrate in the form of wheat starch flour, and protein in the form of an amino acid mix. This formula has an extremely unpalatable taste and was accepted with only great difficulty by the patient. In a volume of this formula of 240 cc there are 1500 calories. This formula was administered in varying quantities at different times throughout his hospitalization. On several occasions during the course of his six-week hospitalization attempts were made to manage the patient with oral electrolyte solutions of various compositions, hypotonic, isotonic, hypertonic, without success. Upon each occasion the diarrhea which supervened exceeded the oral intake and on each occasion the patient became rapidly dehydrated, relatively hypotensive, oliguric, and generally less responsive. The volume of oral intake was limited by vomiting on each occasion which presumably is due to two factors: (1) functional gastric stasis secondary to his vagotomy and pyloroplasty and (2) colonic strictures which developed post-operatively in the distal transverse and sigmoid colon. These latter anatomical obstructions no doubt represent ischemic injury to the colon presumably at the same time as the initial abdominal catastrophe but of a less significant degree resulting in inflammation and stricture instead of frank necrosis and gangrene. On several post-operative barium enema examinations performed over a period of several weeks these strictures were noted to increase slightly with no suggestion of resolution. The strictures have been the greatest stumbling block to adequate oral alimentation since volumes of fluids necessary to combat dehydration were not well tolerated and resulted in vomiting. On two occasions during his admission to the Clinical Research Center the patient developed high temperatures of the order of 104°. The first of these was associated with signs and symptoms of pneumonia at the right lung base posteriorly, and an infiltrate was noted on his chest x-ray. This infiltrate cleared on subsequent chest x-ray. The second episode of fever was presumably related to sepsis from an indwelling venous catheter. Blood cultures at that time were negative and again the episode was self-limited on antibiotic therapy. Because of recurrent phlebotic and generally poor veins the patient has required repeated placement of his IV needles. On two occasions because of unavailability of any veins for needle placement, surgical cutdowns in the cephalic veins

of both arms were performed. The first of these was left in 96 hours and was removed upon the development of fever. The second, placed in the left arm, was also left in 96 hours and removed without incident. On February 6, 1969, the patient complained of a mild frontal headache and through the day became progressively weaker. Through that evening and into the next morning the patient slipped progressively into coma and became increasingly less responsive. There was no readily identifiable electrolyte imbalance and physical examination failed to reveal any localizing signs suggesting a focal intracranial process. After neurological consultation it was felt that the most likely explanation for his progressive obtundation was a metabolic encephalopathy. The patient was placed NPO and maintained on intravenous fluids through this period. A lumbar puncture revealed no abnormalities of the cerebrospinal fluid. Blood ammonia was normal. As gradually as the patient slipped into his comatose state he gradually recovered and by the morning of 2/10/69 had again resumed his previous state of consciousness. At this juncture the family expressed a deep desire to have the patient return home. After thorough and elaborate discussion with the family, explaining the obvious shortcomings of care of such a patient at home, it was agreed to allow the patient to spend the remainder of his remaining life at home. The family and the patient (through the services of an interpreter) understood that such a move would not only compromise the level of his care but undoubtedly shorten his survival. The patient and his family had absolutely no question in their minds that this was what they desired. Accordingly elaborate plans to maintain the patient at home were instituted involving the services of the doctors, nurses, dietitians and social workers who have been and will continue to be involved in his care. Laboratory studies at the time of discharge were: sodium 136, potassium 3.8, chloride 104, bicarbonate 23.1, urea 9; hematocrit 37%, hemoglobin 11.3 gms%, white blood count 4,900.

IMPRESSION

- (1) Status post massive small and large bowel resection secondary to ischemic infarction.
- (2) Rheumatic heart disease with aortic insufficiency-- presently well compensated off all cardiotoxic drugs.
- (3) Malnutrition, moderate, secondary to inadequate nutrition secondary to (1).

DISPOSITION

The patient is discharged to his home where he will be followed by his family physician, Dr. Harold Steinberg; Mrs. Wald, former dean of nursing at the university, who is presently involved with the patient as part of a program of continuing care for the dying patient, will be involved in his care at home as well as members of the Visiting Nurses' Association of Norwalk. Doctors involved with his care during this hospitalization will also maintain a liaison with Dr. Steinberg and the involved nurses. Arrangements have been made for the patient to remain on intravenous fluid therapy which will be handled by his nurses according to directions outlined by his doctors. Because of the problem of maintaining a patent IV in this patient, a surgical cutdown will be placed immediately prior to his discharge. While in the hospital the patient was getting frequent injections of folate, vitamin B₁₂, iron, and vitamin K on a PRN basis. The patient will be given injections of each of these medications immediately before his discharge and subsequent injections will be arranged by his private physician. The only medications the patient will receive will be Bismuth subcarbonate and Metamucil, 2 teaspoonfuls each q.i.d. He is to receive 15 cc of the wheat starch flour diet mix hourly x18 through the day with no feedings during the night. He is to have fluids ad lib as tolerated. He will also be given a list of simple food stuffs, such as jellow and bouillon from which list the family is to select one item to be given daily as a supplement to the basic formula mix. It is to be emphasized that the doctors and nurses in this patient's care feel that his removal from the hospital to home is deleterious to good medical care but in the context of this medical setting with its obvious grave prognosis, the decision of the family to take the patient home was considered reasonable. Extensive information regarding the rather complex care of this patient will be provided his physicians and all other personnel involved in his care at home.

APPENDIX II

INSTRUCTIONS FOR MR. X'S CARE AT HOME

1. The most important aspect of satisfactory management of this patient at home will be proper regulation of his diet. It must be clearly understood that any food product other than the diet mix which the patient is taking in the hospital is harmful to the patient. Mr. X has virtually no intestines to absorb food products into his system. Accordingly, all food supplied to the patient must be in the very simplest form. Unfortunately food in this form is extremely distasteful. We have shown by studies conducted in the hospital that he does absorb significant amounts of this special diet mix but that he is unable to absorb any calories from other simple foods. Not only do these other foods not provide any nourishment but they are also harmful in that they produce significant diarrhea. The family will be provided with a list of simple food products from which they may select a single item in addition to the basic diet which they may give him each day.

The following instructions must be followed for mixing the basic diet mixture. There are three basic constituents to this diet:

- (1) Product 7010-X MCT Oil supplied in gallon cans.
- (2) Stuart's amino acids supplied in glass bottles.
- (3) Cellu wheat starch flour supplied in paper bags.

These should be mixed in a Waring blender in the following manner. Add $3/4$ cup MCT oil to blender. To this add $1/3$ cup of Stuart's amino acid and $1\ 1/4$ cup Cellu wheat starch flour. Blend this for several minutes until it has an even consistency. This mixture will not require refrigeration. On sitting, however, it will settle slightly and should be stirred before each feeding. The patient should be given one level tablespoon of this mixture each hour throughout the day for 18 hours. He need not receive any diet mixture through the night.

The above constituents of this diet mix will be provided to the family after Mr. X's discharge. We will provide sufficient quantities to last approximately two weeks and also supply the family with information as to where they can obtain further quantities.

I must re-emphasize again that any food product other than this diet mix not only provides no nutrition but also is HARMFUL to the patient.

II. The other important aspect of Mr. X's maintenance at home will be proper management of his IV fluids. While these IV instructions will be made as simple as possible, it is critical that the order in which the bottles are used and the proper timing of changes of the fluids is closely followed. Essentially there will be two different types of fluids. One bottle will be marked 5% Dextrose in Half Normal Saline and the other 5% Dextrose in Water. Mrs. Wald will be concerned with adding the appropriate medications to these bottles. The only responsibility which the family will have is to make sure that these bottles are used alternately, first a bottle of 5% Dextrose in half normal saline to be followed by a bottle of 5% Dextrose in water which in turn is to be followed again by 5% Dextrose in half normal saline and so on. Each bottle is to run in over a period of 6 hours so that the family should follow a very close schedule, checking the IV constantly to make sure that the fluids are neither running in too fast or too slowly. A permanent intravenous catheter will be placed just prior to the patient's discharge. This will be a very precious route of administration of intravenous fluids and must be carefully protected. If a bottle of fluid is allowed to run in too quickly and another is not hung promptly, this catheter will clot and will no longer be functional. This will then necessitate returning the patient to a hospital or doctor's office where another intravenous catheter or needle will have to be placed.

Under no circumstances should the family make any changes in either the patient's diet or his schedule of intravenous fluids without first checking with either a nurse or one of the patient's physicians.

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