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The hospital patient's experience of caring and non-caring.

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THE HOSPITAL PATIENT'S EXPERIENCE OF CARING AND NON-CARING

A Dissertation Presented

by

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DEDICATION

TO MY HUSBAND, FATHER, AND DAUGHTER

for their endless love, support, confidence, endurance and faith in my ability.

TO THE PATIENTS WHO PARTICIPATED IN THIS STUDY

for sharing their stories, concerns, fears, and perspectives about hospitalization.

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A special thanks to the University Hospital where this research project took place. The dedication and pride of the staff is reflected in the patient´s story. I finish this research with an even greater appreciation for the work that physicians and nurses do in their daily care of patients.

My sincere appreciation and thanks goes to all the patients in this study who helped me see the world from the eyes and soul of a patient. It is a different world than that of a care provider.

ABSTRACT

THE HOSPITAL PATIENT'S EXPERIENCE OF CARING AND NON-CARING

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Little research has been done on the phenomenon of caring. Although health professionals express concern about the care they provide to patients, caring has not received the same degree of scholarly inquiry as the study of cures.

This study attempts to shed some light on the phenomenon of caring from the patient's perspective. The primary purpose was to discover those experiences that hospital patients perceived to be caring and non-caring. The secondary purposes were to (1) determine if there was a gender difference in patient perception of caring and non-caring experiences, (2) determine if severity of illness was a variable in how patients perceive caring and non-caring, and (3) discover if patients perceive a difference in caring and non-caring in the past five or more years.

This study followed an interpretive paradigm of research and analysis. It attempted to both describe human experiences as it appeared, and to understand the significance of the experience to the individual.

The interpretation and analysis of findings are presented using metaphors (Chapter 5). Five metaphors are used to describe patients expressions of caring, and four are used to express patients descriptions of non-caring.

All patients had some thoughts and ideation about loss, death and dying, regardless of their diagnosis. Findings suggest that nurses may underestimate the patient's desire for frequent surviellance. Care providers who demonstrated a holistic view of the patient and an understanding of the patient's personal needs were perceived to be caring.

The emergence of a hierarchy of nursing care and medical care needs are suggested by the data. Patients appear to have a different hierarchy for nursing than for medical care. Although this was not part of the research question, it seems important and worthy of further research.

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CHAPTER I

INTRODUCTION

Background

A health care institution by its very nature is designed to provide care and treatment to the sick and injured of our society. The underlying values of a hospital are built upon humanistic goals designed to meet the needs of the patient. It is a human service organization in which society has bestowed (upon the hospital and physicians) substantial power, prestige, and pecuniary rewards in return for the care it provides (White, 1973). This social contract, a relationship noted by the French philosopher Rousseau, is an expression of interdependence between the health care system and the society that it serves (Piper, 1986).

The health care system is presently going through a radical transformation, as are many other human service organizations in our society. The recent changes in reimbursement for Medicare, Medicaid and H.M.O.'s have acted as a major catalyst for these changes. Since medicare patients make up thirty five to seventy percent of a hospital's patient census according to the American Hospital Association

(A.H.A.,1987), hospitals are being forced to change the way they do business.

The dramatic reduction in reimbursement for patient care has required hospitals to emphasize greater productivity and cost containment. Hospitals are being forced to do more with less. Third party payors (government, H.M.O. and insurance companies) are paying hospitals based upon pre-determined lengths of stay which do not adequately adjust for severity of illness. Patients are complaining of being discharged sicker and quicker than they were a few years ago. Some hospitals are actually refusing admissions to patients who are unable to pay for their hospitalization by transferring them to other hospitals.

In Massachusetts, two thirds of all acute care hospitals reported a financial deficit in 1989 according to the Massachusetts Hospital Association (M.H.A., 1989). Greater emphasis is being placed on competition among hospitals for capturing a market share of product lines (patients).

As a hospital administrator, I have noticed that many health professionals place greater emphasis upon the care of technology than upon the care of the

patient. The present focus on cost containment by the government and insurance industry may erode the institution's ability to provide personalized patient care, thus changing the nature of our present health care system.

Piper (1986) contends that hospitals are becoming an economic commodity and no longer focus upon altruistic goals. Health care literature has recently shifted its writing to focus on such topics as strategic planning, economic survival and the challenges of the marketplace.

A pilot study of three patients in a teaching hospital in the northeast was conducted by the researcher in the summer of 1988. The study gathered data on the patient's description of caring and non-caring experiences which they encountered in the hospital. While there are many health providers who contribute to the experience of a patient, the research focused only on the patient's perception of the ability and willingness of the nurse and physician in creating a caring environment. The data suggested that patients describe a caring person as one who:

- is knowledgeable and technically competent;
- provides surveillance and protection;

- communicates and instructs patients about procedures, exams and plan of care;
- produces positive outcomes;
- is able to alleviate stress, pain, and discomfort;
- anticipates the patient´s needs; and
- provides emotional support and understanding.

The data also suggested that the presence or absence of non-caring experiences appeared to be influenced by the patient´s length of stay, severity of illness , personality traits and gender. The research findings, however, were too sketchy to draw any conclusions other than to pose additional questions. The pilot study, however, did provide evidence that patients can and will describe experiences which they perceive as being caring or non-caring (Frieswick, 1988).

Blattner (1985) Ray (1978) Watson (1976) and other authors support the notion that "caring" is the underlying goal of a hospital. Leininger (1978, p.3) postulates that "caring is an essential human need for the full development, health maintenance, and survival of human beings in all world cultures". DiMatteo and

DiNichola (1982) and Leininger (1978) contend that caring can exist without healing, but that healing cannot exist without caring.

Little research has been done on the phenomenon of caring. Although health professionals express concerns about the care they provide to patients, caring has not received the same degree of scholarly inquiry as the study of cures. Females throughout history have provided many kinds of caring to individuals and groups. Most western cultures view caring as a feminine activity and curing as a male activity (Leininger, 1978). In countries like China and Russia where most physicians are female, the culture bound definitions of caring and curing appear to blend together (Brenner and Thompson, 1986). The social status of the medical profession in both of these countries, however, is not as revered as that in the United States. These conclusions suggest that the cultural influence upon gender, role expectation and caring cannot be ignored.

As a word, "caring" does not have one determinant definition or a significant meaning that is understood in all contexts; rather, it has a family of meanings, and its meaning shifts across contexts. The word may be considered both vague and ambiguous. Most studies

reported in the literature, such as Leininger (1978), Germain (1979), Gaunt (1984), and Lazare (1987), have focused on the health provider's perspective of what constitutes caring or non-caring behavior. Little is known about the patient's perception of caring and whether the patient's perception of caring is the same as health providers'. Leininger's research suggests that western health providers and patients differ in their idea of what constitutes caring behavior (Leininger,1978). If this finding is true, then we need to better understand the needs and perceptions of the patient for caring.

Purpose Statement

Caring is a very influential factor in the promotion of health and healing (Leininger, 1978; DiMatteo, and DiNicola, 1982). Traditionally physicians, nurses, and other health professionals have used the phrase "I care" or "I gave care to that patient". Since most of the research on caring has only focused upon the provider's definition of caring, we do not know if the care we provide meets the needs of the care recipient. Since the primary purpose of the health care institution is to meet the health care

needs of patients, it is important that we have a clearer understanding of the patient´s perceptions of caring.

Therefore, the purpose of this study is to shed light on the phenomenon of caring from the patient´s perspective,especially on those experiences which the patient perceives as demonstrating caring and non-caring. It also seeks to determine if male and female patients in this study have similar experiences, and if males and females describe caring and non-caring in the same terms. A secondary purpose is to determine if the patient´s perception of caring or non-caring experiences in the hospital were similar or different from those which the patient may have experienced in previous hospitalizations.

In this study the researcher shifts her thinking to the perspective of the patient, to understand how the patients perceive their experiences. This study provides an alternative approach to the study of the phenomenon of caring. It uses a qualitative approach since there is little known about the patient´s description of caring or non-caring. Interviews will take place while the patient is hospitalized and during the post hospitalization period. The researcher will be

required to take on an interpretive mindset to fully gain a clearer understanding of how the patient interprets experiences as being caring or non-caring. The researcher will attempt to get into the mind and body of each patient in order to understand and see the world from his/her eyes. This approach has been described by Meltzer et al.,(1975,p.51)as "sympathetic introspection" and by Bogdan and Taylor (1975,pp. 13-14) as "verstehen". In order to retain the integrity of this phenomenon, the researcher will need to bracket her own understanding of caring and non-caring and attempt to only see the patient's perspective (Burrell and Morgan, 1979).

Research Questions

This research study seeks to answer five questions, two primary questions, and three secondary questions.

Primary Questions:

1. What are the experiences that hospital patients perceive to be a demonstration of caring?

2. What are the experiences that hospital patients perceive to be a demonstration of non-caring?

Secondary Questions:

1. Do female and male patients perceive demonstrations of caring and non-caring similarly, or are there gender differences?

2. Is severity of illness a significant variable in how patients perceive demonstration of caring and non-caring?

3. Do patients perceive a difference in demonstrations of caring and non-caring from what they experienced five or more years ago?

Significance of the Study

The educational process of health professionals should include knowledge of what constitutes caring behavior and an understanding of the patient's perspective about behavior that is interpreted as being non-caring. Health professionals would benefit from a better understanding of the patient's description of caring, rather than assume that the patient shares their same understanding and meaning. Therefore, this research will contribute to our understanding and knowledge of this phenomenon by expanding our understanding of the patient's perceptions of caring. Secondly, the discovery of this knowledge could provide data to hospitals on how they could change practices and better support the needs of patients for care.

Third, the findings may lead to suggestions on how this new knowledge could be incorporated into the curricula of medical and nursing education as well as that of other health care providers. Findings may also lead to further research questions.

Definition of Terms

Caring : The term "caring" is understood by health professionals in both the scientific and humanistic definitions. "Scientific caring refers to those judgments and acts of helping others based upon tested or verified knowledge, whereas, humanistic caring refers to the creative, intuitive or cooperative helping process for individuals or groups based on the philosophical, phenomenological, and objective and subjective experiential feelings and acts of assisting others" (Leininger,1978, p.47).

Interpretive Paradigm : An organizational theory that has as its primary concern an understanding of the subjective experience of the individual. Interpretive theorists attempt to construct the individual actor´s perspective. They believe that reality rests in socially constructed webs of symbolic relationships that are continually negotiated and renegotiated. Research is concerned with documenting the interactions

of organizational members throughout these processes (Burrell and Morgan, 1979). Therefore, research tends to involve rich descriptions of subjective experience.

CHAPTER 2
LITERATURE REVIEW

Introduction and Scope

This review will summarize the literature on the phenomenon of caring. Since little research has been done on the patient's definition of caring, the literature was reviewed to determine how philosophers, psychologists, physicians and nurses define caring. The chapter is divided into five parts: the first section looks at the definition of caring from different disciplines; the second section describes ingredients of caring and non-caring relationships defined by philosophers, physicians and nurses; the third section looks at variables which appear to affect the perception of caring, such as gender, social-cultural background, personality traits, and absence or presence of stress and illness; the fourth section looks at the care-givers perspective of caring, and includes the findings of both medical and nursing research; and the last section summarizies research findings on the patient's perception of caring in hospital and ambulatory care settings. Since the focus of this research is to describe the patient's experience of caring and non-caring in a teaching hospital, the literature serves as a framework for gathering and analyzing data.

Part I : Definitions of Caring

The word "care" has been used in medicine and nursing as a verb, as "caring for others" or to manifest care with concern, compassion and interest in the well being of another person. Care and caring seem to have multiple conceptualizations and characterizations.

Leininger,(1978) describes caring as an art form with theoretical, philosophical, and practical aspects which requires study in order to understand the complexities of the phenomenon, and to develop the skills needed to deliver the care. It is an art form in much the same way that Fromm declared love is an art. It is an essential part of the practice of both medicine and nursing, and is probably the only part of the practice that the patient is able to easily evaluate. Leininger (1978, p.9) defines care/caring as:

> those assistive, supportive, or facilitative acts toward or for another individual or group with evident or anticipated needs to ameliorate or improve a human condition or lifeway.

May (1962, p.286) offers some ideas about caring in his discussion about humans relating and living in their environment. He defines caring as:

> a feeling denoting a relationship of concern when the other's existence matters to you; a relationship of dedication, taking the ultimate terms, to suffer for, the other.

May posits that to do something about a situation you must have objective facts, and make decisions. To do this it requires the care giver to bring "love and will together" (p.287). According to May, when someone matters to us we are willing to extend energy in structuring our life so that positive things happen to and for the one we care about.

Heidegger (1962,p.32) speaks of care as "the source of the will". For him the will is the driving force of life, and care is its source. He speaks of caring as the basic phenomenon of human existence inclusive of the sense of selfhood. In other words, we lose our selfhood, our being, and our will. In not caring our being disintegrates. Heidegger sees caring as equivalent to the will or motivating force of life.

Bevis (1981, p.50) draws upon the works of May and Heidegger and defines caring as "a feeling of dedication to another", to the extent that it motivates and energizes action to influence life constructively and positively, and by increasing intimacy and mutual self actualization. Bevis proposed that caring has four

stages: attachment, assiduity, intimacy and confirmation. Each stage is contingent upon the completion of the previous stage.

The emphasis on helping and enabling activities of individuals, or groups, is a common thread in all definitions on caring. The activities needed to enable the individual or group, however, vary with the situation and the culturally defined and prescribed beliefs, values, and practices, as we shall see further in this chapter.

Part II : Ingredients of a Caring and Non-Caring Relationship

Description of a Caring Relationship

Philosopher Milton Mayeroff´s (1971) thoughts about caring strongly parallel those of the humanistic psychologists Carl Rogers, Erich Fromm, and Rollo May. However, major difference in Mayeroff´s work is his detailed description of the elements required in the caring process; knowing, alternating rhythms, patience, honesty, trust, humility, hope, and courage. Since this research seeks to discover those behaviors which the patient defines as caring and non-caring, a more detailed explanation of Mayeroff´s description of caring is included.

According to Mayeroff (1971) there are many kinds of knowing. Explicit knowing is being able to articulate knowledge about something or someone to another person. Implicit knowledge is sensing information but unable to express it, as the professional who gives a nonverbal nod to a patient that he/she understands the patient´s sorrow.

Intuitive knowing can be considered knowing in that knowledge or feeling is sensed in a manner that is not obtained by normal means (Mayeroff,1971). This kind of knowledge has not been widely accepted by the scientific community, but is gaining increased acceptance in the western world. Intuitive methods of gaining information such as "psychic" assessment data gathering are beginning to be used by many holistic practitioners (Blattner,1975).

According to Mayeroff (1971), knowing a person in a caring relationship is knowing her/his strengths and weaknesses, aspirations, and wishes. Professional competence requires the practitioner to have additional knowledge about health and illness, human behavior and development, communication, and problem solving and to be able to apply this knowledge and skill to the individual patient .

"Alternating rhythm" is a phrase which Mayeroff (1971) uses to describe the capability for taking different perspectives or points of views on a problem. It is the ability to look at a situation from a broader point of view, to see the critical incident in its proper historical perspective, and to look at the long term ramifications of a decision. The practitioner who can see and accept the cancer patient´s decision not to take chemotherapy, and to die at home surrounded by family members may be an example of alternating rhythms.

The professional who allows the patient the space and time to grow at his/her own pace and accept personal responsibility for his/her own care is an example of Mayeroff´s (1971) concept of patience. Many nurses and physicians find it difficult to allow a patient decision making power in the plan of care. Patient involvement in the care was not an expectation in the past, and clearly is a change in role and expectations. According to DiMatteo and DiNichola (1981), the practitioner in the past was always seen as the all knowing, nonjudgmental healer who was supposed to be neutral, portraying little emotion. This assessment behavior of the physician often created an air of superiority. The patient on the other hand

played the role of the passive recipient, expected to fully cooperate with the physician. Mayeroff"s description of a caring relationship obviously disagrees with this old image. This vision advocates a collaborative relationship between the care provider and care recipient.

Mayeroff (1971) also describes the caring relationship as an honest relationship. He stresses the need for the care provider to be honest about his/her own thoughts, weaknesses, and motivations for providing care before entering into the relationship. This implies that the professional must be honest about his/her goals, and secure in his/her own knowledge and skills to be able and willing to negotiate goals with the patient.

Humility, according to Mayeroff (1971), prevents the enthusiastic helper from overwhelming the patient with sympathy and understanding or smothering them with concern. When this happens the professional has identified so closely with the patient that the problems and solutions are taken on as ones own. Mayeroff contends that humility prevents the practitioner from overreacting to the patient with sympathy, by helping the professional to realize that

his/her "particular caring is not in any way privileged" (Mayeroff, 1971, p.87). Therefore, patients are not viewed as being "mine" or "yours", but are seen as individuals who cannot be controlled and as persons from whom we can learn.

Reliability and honesty help to establish trust in the practitioner-client relationship; it is an essential ingredient in a caring relationship. Trust is required for an individual to allow himself or herself to be vulnerable to another. DiMatteo and DiNichola (1982) note that low self esteem leads to feelings of vulnerability and mistrust. Waterman (1981) contends that trust is most readily established when the patient has had some input into the selection of the individual whom he/she must trust. Waterman's notions about trust suggest that the practitioner and patient relationship could be enhanced if the practitioner placed emphasis on developing within the patient a sense of personal responsibility about his/her care.

Hope is an ingredient of caring which maintains the desire to want to continue caring. An example of this is seen in the cancer patient who is empowered by the practitioner to have a sense of hope, and therefore gains the inner strength to continue with life .

Care takes courage, for it is difficult to care for an angry, abusive patient. It is also difficult for a nurse or physician to care for patients who are dying. Courage can also be seen in the eyes of a patient who is a trauma victim or a patient who must be hospitalized for a prolonged period.

Characteristics of Non-Caring Relationship

According to Bevis (1981), if we reduced caring to its natural state it would produce only positive responses. But care is a matter of perspective. It is this researcher´s belief that some attempts at caring can produce a negative response if the recipient of care perceives the care giver as inhibiting his/her behavior, or the care activity is perceived as being unwarranted, or given in an uncaring manner. What may be perceived as caring behavior by one, may be perceived as uncaring by another.

Lazare (1987) found that the patient´s perception of caring is influenced by the social structure, and that disease itself influences and changes the patient´s self image. Disease is frequently perceived as a personal defect, inadequacy, or shortcoming according to Lazare. Patients may experience a sense of shame and humiliation because they are ill, and may

feel humiliated or shameful by the manner in which the care is administered. Shame and humiliation refer to the painful feeling caused by a lowering of ones pride, self-respect, or self-esteem.

According to Lazare (1987) physicians and nurses have the ability to influence the patient´s experience in the hospital. Patients who feel depersonalized during hospitalization often feel their health care needs are not being met, and that they are an imposition to the provider and the complex bureaucracy, rather than the reason for their existence.

The most abstract characteristic of a caring person is perhaps the ability to see the other as a unique individual, to perceive the other´s feelings, and to be able to set apart one person from another. The uncaring person is by contrast, insensitive to the human traits of the patient and is unable to see the patient as a unique human being who is distinguishly different from the "gallbladder in room 204".

Part III : Variables Appearing to Affect Caring

Social-Cultural Influence

Leininger (1978) found in her transcultural study of nurses that the definition and description of caring

is culture bound, and may be defined differently by nurses, physicians and patients. She found in several non-Western cultures that both the nurse and the patient perceived caring as protective and surveillance acts and processes, and both placed greater significance on instruction and health promotion than Western nurses. In contrast, she found Anglo-American nurses perceived caring as an alleviation of stress through technologic aides, medicines and psychophysiologic comfort measures. She also found that not all Western patients shared this definition.

The use of touch as a therapeutic medium of care has fallen into disuse in Western countries during the twentieth century with the advent of technology, scientific research, and modern medicine. Therapeutic touch as described by Dolores Kreger is basically a healing medication in which the process of therapeutic touch involves centering and maintaining that center throughout the healing process (Kreger, 1979). Examples of the use of touch are described in Eastern medicine with such techniques as acupuncture and psychic healing.

Patients may not perceive touch as a gesture of a caring or warmth according to some research findings.

According to Leininger (1978), touching is also seen in some non-Western cultures as a non-acceptable social behavior. Therefore, practitioners need to understand the context in which touch can be used to create a therapeutic medium for care.

Watson´s (1983, p.205) cross-cultural data on caring in nursing suggests that "treating the individual as a person," and "personalized characteristic of the nurse" may influence the patient´s perception of caring. The nurse´s ability to communicate to the patient a feeling of being special or having received an "extra effort" from the nurse influenced the patient´s perception of receiving good care. Watson found in her study on human caring among Australian, Anglo-Saxon, Aborigine, Chinese and Taiwanese a strong and consistent linkage between the phenomenon of caring and the personalized responses of the nurse.

Watson´s (1983, p.55) cross-cultural analysis of caring includes such things as: the presence of the nurse, as expressed by such behavior as touch and physically "felt presence"; exchange of feelings of love; sharing of sorrow or pain; and surveillance. All of these findings are consistent with the individual

approach, and conscious acts that convey a will and intent to care, along with specific actions.

Parker(1981) contends that our cultural beliefs have influenced our concepts and practices toward illness and death. He argues that in Western culture death and suffering have become a taboo topic for the following reasons: a) loss of traditional religious beliefs; b) medicalization and specialization in the care of the sick has removed the sick from the common experiences of home and daily living to the hospital; c) movement toward a consumer-oriented, materialistic society that values replacement of the old with the "brand new", thus de-emphasizing and avoiding loss; and d) an association of good health with "cleanliness" combined with an obsession with youth which leads to an avoidance of death as a disintegration and decaying of the body.

Empirical research on transcultural caring has supported the above view that caring is influenced by cultural beliefs, mores, values and customs. Research also indicates that within a culture there is a personal response to illness, and caring that is influenced by ones own personal experiences within the culture (Leininger,1978).

Gender and Its Affect on Caring

Inquiries conducted in both medicine and nursing suggest that gender may influence the expectation of a caring relationship. Francis, Korsch, and Morris,(1969) and Freemon, Negrete, Davis and Korsch (1971) investigated various aspects of the physician-patient relationship in a pediatric clinic and emergency-room setting. Conversations between practitioners and mothers in an emergency room setting were tape recorded and coded to the specific behavior exhibited and each case history was reviewed. Mothers were interviewed to assess their expectation and evaluation of the medical encounter during the initial visit and again two weeks after the medical encounter. Findings showed mothers were significantly more satisfied with visits when the pediatrician was judged by independent raters of the taped recordings to be friendly and concerned. Results also revealed that the greater the friendliness of the physician toward the mother during the interaction, the greater the compliance to the medical plan of care.

Another study conducted by Swanson-Kauffman (1986, p.86) found that women who had experienced a miscarriage desired five kinds of caring: a) caring which involved knowing the woman´s loss is "unique" to her as a person; b)"being with" the woman in an engaged

manner; c)"doing for" the woman by providing comfort and support measures; d) "enabling " the woman to grieve for the loss of the child; e)"maintaining the belief" that the woman could bear another child. The data suggest that the "relationship" between the woman and the care provider is highly valued by females.

The question "Do males have a different notion of caring?" was studied by Weiss (1984). The findings suggest that males place greater emphasis on the technical aspect of caring than do females. Weiss attempted to determine whether verbal and nonverbal caring and noncaring behavior and technical competency or incompetency in the nurse-patient relationship were perceived as caring by male and female patients.

Subjects consisted of 240 college students who were equally divided between sexes with a mean age of 22 years and age range of 17 years to 45 years. A factorial experimental research design was used to test the simultaneous effects of the independent variables on the dependent variables. The independent variables included 1) communications of verbal caring and uncaring, 2) non-verbal caring and uncaring behavior, 3) behavior which displayed technical competency and

incompetency of the nurse, and 4) sex of study subjects. Videotape segments provided the method through which the manipulations were performed.

Three instruments were used to rate the subjects response: 1) The Social Distance Scale to measure the sympathetic understanding and person-group distance; 2) Kirchner's Attitude of Special Groups Toward the Employment of Older Persons Scale; and 3) The Slater Consistent Competencies Rating Scale.

The findings showed that the variables of the verbal and nonverbal behavior and the technical competency were not judged to be statistically significant when tested for interaction effect. Both sexes preferred a nurse who was technically competent and exhibited caring verbal behavior. However, the data did suggest that males tended to use the nurse's technical skills for judging the caring behavior of the nurse, while the female subjects accepted the nurse if she exhibited caring verbal responses even if she was technically incompetent. At the same time males indicated preference for the verbal uncaring nurse as long as she was technically competent.

The research data suggest that gender may influence ones perception and expectation of a caring relationship, and that caring is influenced by the culture in which it is practiced. Goffman (1976, p.130) argues that:

> gender is socially scripted dramatization of the culture's idealization of feminine and masculine nature, played before an audience that is schooled in the presentational idiom.

This notion has been supported by many feminine scholars such as Miller (1976), Gilligan (1982), West and Zimmerman (1987) Roberts (1983) and others. The research data suggest that the phenomenon of caring is influenced by our cultural perceptions of caring and may be influenced by who provides the care (physician or nurse) and gender of the care giver.

Stress and Illness

Stress and illness may influence the patient's perception of the care provider and may alter his/her need for caring. Benner and Wrubel (1986, p.87) define stress as

> the disruption of meaning, understanding and functioning so that harm, loss or challenge is expected and sorrow, interpretation or new skill acquisition is required.

Illness can be seen as an interruption of ones ongoing life. An illness can never be experienced in isolation,

and must be seen within the context of the past and present life cycle of the person. The meaning which a patient or family attributes to the stress of hospitalization or illness willarise out of the transaction of the personal and cultural meaning which are imposed on the event (Benner and Wrubel, 1986).

According to Kleinman, Eisenberg, and Good (1978) health is not the absence of illness, and illness is not identical to our concept of disease. Illness is the human experience of loss of function, whereas disease is the manifestation of aberration at the cellular, tissue, or organ level. A person may have an disease or chronic illness and yet not experience himself or herself as being ill. Furthermore, patients do not experience illness as symptoms that can be medically diagnosed syndromes. Instead the patient's symptoms are interpreted as an inconvenience, or a concern about health. Typically, patients seek the aid of the practitioner to alleviate symptoms and to explain or allay their health concerns (Benner and Weubel, 1987). Many illnesses have no cure, thus patients must learn to cope and adjust their life style to chronic illnesses.

Personality Traits

Personality traits of an individual may influence the patient's response to illness and care. Personality traits and behavior patterns are embedded in the cultural practices, skills, experiences, social norms, and cultural body.

Kahana and Bibring (1964, p.108) defined seven basic categories of personality types: 1) the dependent, overdemanding patient; 2) the orderly controlled patient; 3) the dramatizing, emotionally involved, capitivating patient; 4) the long-suffering, self-sacrificing patient; 5) the guarded, quarrelsome patient; 6) the patient with feelings of superiority; 7) the patient who seems uninvolved and aloof. The authors propose that these personality types are psychologically normal and do not designate personality disorder. They describe each category and formulate the meaning of a physical illness to each personality type.

Part IV : Care Givers Perspective About Caring

Influence of Caring on Curing

Although curing has been the primary focus of medical practice, caring for the patient has also been an intricate part of the art of medicine. Leininger (1978 p. 25) contends that "caring can exist without

curing, but curing cannot exist without caring". It is this researchers belief that the caring ingredients are the same for both medicine and nursing, although the activities and practices may differ.

DiMatteo and DiNichola (1982) agree with Leininger's notion that caring influences healing. They posit that it is the rapport and relationship between the physician and the patient that actually influences the patient's response to healing. They contend that the patient trusts the physician and believes the efficiency of the medical treatment will produce positive outcomes. These factors influence the patient's willingness to participate in the treatment plan. Therefore, it is the caring aspects of medicine which provides an environment which helps to promote healing and health.

Caring as a Central Focus of Nursing Practice

Caring has been described by Leininger (1978), Ray (1984) and Watson (1983) as the central focus of nursing practice. Caring has been described by Watson (1983) as one of life's essential needs, for without care, life would cease to exist. She defines the caring process as encompassing factors that help the person attain or maintain health or die a peaceful death. She

has developed a theory of nursing which embodies human care and includes three major areas:

1. Nursing practices within a human science and art context.
2. Mutuality of person/self is required of both the nurse and patient with a mind-body-soul gestalt, within a context of intersubjectivity.
3. Human care relationship in nursing are a moral ideal that includes concepts such as phenomenon fields, actual caring occasion, and transpersonal caring.

Watson´s theory includes concepts of health, illness, environment, and the universe, and how they interact, transact, and transcend the physical-material objects and values of life. The goal of the theory is associated with a mental-spiritual growth for self and others. Watson believes that through caring the individual finds meaning and discovers an inner power and control, and "potentiating instance of transcendence and self healing" (Watson, 1983,p.74).

Watson´s theory is influenced by Eastern philosophy which assumes a unification of the mind, body, and spiritual nature. Watson believes the

although the patient is the agent of change, the nurse can also be changed through the caring process. It is the personal, inner mental-spiritual mechanism of the person that allows the self to be healed through various internal and external means, or without external agents. It is through this intersubjective interdependent process whereby both persons (the care provider and care recipient) have the potential of transcending their selves and their experiences.

Paterson and Zderad (1976, p.66) support Watson's notion and identify caring behavior of the nurse in terms of an existential view of humans as in the "process of becoming". They argue that the meaning of humanistic nursing is found in the human act itself. The authors explained that the elements of this humanistic framework included incarnate humans (patient and nurse) meeting each other (being and becoming) in a goal directed approach aimed at bringing about a nurturing human state of wellness. Patterson and Zderad speak of nursing as an existential engagement directed toward nurturing human potential.

Caring Contribution to Growth of the Individual

A recurring theme in the writing of selected scholars in the fields of psychology, philosophy,

nursing, and medicine, is the belief that caring refers to the growth of the individual and a movement toward self-actualization. To understand the growth process in a caring relationship, Mayeroff (1971, p.104) characterizes this concept in the following way:

> To help another person to grow is at least to help to care for something or someone apart from himself, and it involves encouraging and assisting him to find and create areas of his own in which he is able to care. Also, it is to help that other person to come to care for himself, and by becoming responsive to his own needs to care, to become responsible for his own life.

Part V : Patient´s Perception About Caring

Although research is limited on the patient´s perception of caring, the literature does provide some insights on selected aspects of caring. Two such studies will be reviewed in this section; a study on the use of touch in a medical encounter, and supportive nursing behavior.

Influence of Touch on a Caring Relationship

Larsen and Smith (1981) evaluated the affects of touch on the patients´ level of satisfaction during the medical encounter. In this study, the researchers videotaped thirty-four patients who were seeing the physician for the first time. After the visit each

patient completed a questionnaire designed to evaluate the degree of satisfaction with the medical encounter, and his/her understanding of the information given. Findings showed that the more the physician touched the patients during their conversation the less satisfied these patients were with their visit. The authors suggest touching may have been interpreted as an aggressive act since this was the patient's first visit, and a trusting relationship was not established.

Supportive Nursing Behavior

Gardner and Wheeler (1981) conducted a study to measure the patients' and nurses' perception of supportive nurturing behavior. A structured interview and questionnaire were used in this study. The sample consisted of 74 nurses and 119 patients. The patient population was made up of 25% surgical cases, 50% medical, and 25% psychiatric patients. The sex of the patients were fairly evenly distributed with 57 males and 59 females patients.

The top three ranking behaviors defined by nurses were: 1) shows interest in patients; 2) creates an environment where a patient feels free to express feelings: and 3) takes time to listen to patients. The three items ranked by patients as supportive in descending order were: 1) nurse helped me to feel

confident that adequate care was provided ; 2) nurse was friendly; and 3) nurse showed interest in me.

Patients and nurses disagree on the importance of 33% of the items used to measure supportive nuturing behavior. Nurses tended to perceive listening and discussing patient´s feelings as more important than the patient did; and patients tended to perceive physical care administered adequately and on time, and the friendliness of the nurse as relatively more important than the nurses. These differences support the notion that patients and nurses may have differing priorities as to what constitutes patient care.

The research data on the patient´s perception of caring in a hospital setting is rather limited. However, the data suggest that the patient and care provider may differ in their definition and expectations of the caring relationship and process.

Most of the research to date has focused on the providers definition of caring. Data from some of the research studies supports the notion that the patient´s definition of care may be different from the practitioners. It also supports the notion that the

social-cultural background and gender of the patient may affect the way the patient defines care.

CHAPTER 3

RESEARCH METHOD

Design

A qualitative research method was used to describe the phenomenon of caring as experienced by patients in a university hospital. Qualitative research is inductive and demands a flexible approach (Taylor and Bogdan, 1984). It refers to research that produces descriptive data about people and their experiences using their own words and observable behavior.

Qualitative research has been described as naturalistic. The researcher interacts with the informant in a natural manner and as unobtrusive as possible. In in-depth interviewing, the researcher attempts to formulate the interview question into the normal conversation, thus questions flow from within the context of the interview process. Although it is impossible to completely eliminate the influence of the researcher on the people within the study, attempts are made to minimize or control those effects or to at least understand them when interpreting the data (Taylor and Bogdan,1984). By observing people in their daily setting and obtaining from them first hand knowledge of social life which is unfiltered through concepts, operational definitions and rating scales,

the researcher is better able to fit the data to what people say and do (Burrell and Morgan, 1979). Phenomenologists view human behavior from the subject's point of view. A descriptive phenomenological methodology consists of "describing or explicating experience in the language of experience" (Watson,1983,p.80). It attempts to not only describe the human experiences as they appear but also to understand their importance or significance to the individual. Therefore, the subject matter of phenomenological research is always human experience, such as loss, grieving, anxiety, hope, despair, love, caring, humiliation, shame, and other related human experiences and concepts of existence.

A phenomenological analysis requires the researcher to bracket the existential and historical aspects of experiences and concentrate on the "essence" or the "ideal types" exemplified by the experiences that we have or conceive of having (Watson, 1983 p.80). Phenomenological studies such essences and clarifies the various relationships between them.

The human phenomena of caring and non-caring are not object like. Therefore in this study, caring and non-caring cannot be viewed as neutral terms that are

detached and independent descriptions of an experience. Instead they must be studied by understanding the modes of their existence and the meaning which the patient gives to each experience. The human phenomena of caring and non-caring is made known to the researcher through the moods, feelings and emotions which the patient experiences.

According to Burrell and Morgan (1979), Watson (1983), Merleau-Ponty (1962), and others, the key to phenomenological research is that the researcher must take into account the way the world is experienced by the subjects; this requires "phenomenological reduction". It consists of analyzing not only what is experienced but the mode or manner in which it is experienced or its essence.

The phenomenological reduction method is a two-step procedure (Merleau-Ponty, 1962, p.198) :

1. The experience is bracketed, held in suspension, and regarded as an appearance.
2. The experience phenomenon is imaginitively varied to obtain the invariant feature of the phenomenon in order to discuss the necessary structure of the experience, or the "essence" of the phenomenon .

The concept of essence requires the deepest inter-subjective agreement of a given context.

Intersubjectivity consists of having others independently describe a phenomenon as experienced and reported, and then comparing the results. It requires the researcher to step back from the lived experience and reflect upon it. What is the necessary structure of that experience and what must it be like to have these perceptions occur? It is a "reflective orientation" (Watson 1983, p. 84).

Blummer(1969) describes three basic premises of phenomenologic symbolic interaction:

1. people act toward things and people on the basis of the meaning they give to events and people;
2. the meaning of things, persons, or acts grows out of the way other persons act toward the person or event; and
3. individuals attach meanings to situations, individuals, things, and themselves through a "process of interpretation" (Blummer, 1969,p.4)

The actor selects, validates, or changes meanings based on the situation and his/her experience. The

process of interpretation acts as an intermediary between meanings and can serve as a script on how to act in a given situation. From this perspective, we as individuals are constantly interpreting and redefining things as we discover new meaning, and as we become transformed by our own life processes. Taylor and Bodgan (1984) describe the process of interpretation as a "dynamic process". Therefore, how patients interpret their hospitalization and care will depend upon their life experiences and the meaning attributed to each of these events. It was this dynamic process of interpretation of care that the researcher sought to discover in this study.

Methodology

Patients were studied within the context of their experiences in the hospital using a holistic approach. The researcher´s task was to analyze the ways a patient applies both the abstract culture bound rules of the hospital and his/her own common sense understanding of caring. To do this the researcher attempted to view the hospital from the eyes of the patient and broaden her own understanding of the hospital reality and caring. The goal was to discover the patient´s interpretation of the caring received and to describe his/her notion of what constitutes caring and non-caring behavior.

Both the review of literature and the pilot research study conducted by the researcher suggest that a patient's perception of this experience of caring may be influenced by variables such as the 1)severity of illness, 2)length of stay, 3)gender, and/or 4)the social cultural background of the patient (Field Notes, Pilot Study, July-August 1988). Other factors now unknown to the researcher may also have influenced these patients' perception of caring. Since all patients experience an admission process, diagnostic tests and teaching rounds, the researcher asked the patient to specifically describe these experiences. The purpose being to determine if the patient perceived that the nurse and physicians created a caring environment during these similar experiences.

Patients were also asked to compare the caring they received during this hospitalization with caring they received during a hospitalization that occurred five years or more. The purpose being to determine whether patients noticed a difference in the caring or non-caring experiences of hospitalization.

Research Site

The Medical Center selected for this study is a 375 bed University Hospital located in the Northeast,

U.S.A. The researcher has been employed at this setting in various leadership roles for the past ten years. The identity of the researcher's position within the organization was protected throughout this study in order to prevent any patient bias on information shared with the researcher.

Of the total bed capacity of this hospital nineteen percent (19%) of the beds are intensive care and intermediate care beds, as compared to a range of 5-8 % in other community and university hospitals within the state. Patients in this setting therefore, are sicker than in other settings.

The University Hospital is a level one trauma center for the region, so it receives trauma victims from a one hundred mile radius. It is also known for its excellence in cardiovascular care, thus patients from all over New England are referred for cardiology, cardiovascular surgery, and cardiac surgery.

The demographics of the patient population within the Medical Center are relatively young, with only thirty five percent of the patient population eligible for medicare or over sixty-five years old. The

hospital, as with most hospitals, has a slightly higher population of female patients than male patients.

Selection of Sample Population

Both the pilot study and the literature suggest that the patient's gender may influence his/her perception of caring and non-caring. Therefore, the sample size is sixteen adult medical/surgical patients with an even number of male (8) and female (8) patients.

Patients were randomly selected from a computerized listing of even numbered (2,4,6,) patients admitted on a Monday or Tuesday. Patients were omitted if they were critically ill, unable to speak English, under eighteen years of age, knew the identity of the researcher or if consent was not granted from the physician, the nurse or the patient in that order. Since the sample is an even number of male and female patients, every other patient selected was a female. If for any of the above reasons the patient was discarded from the sample, the next even numbered patient was selected.

Monday admissions were selected for the first four patients but were later discarded because most of

these patients were discharged by Saturday when the interviews took place. Therefore, the remaining patients were randomly selected from a list of patients who were admitted on Tuesday.

Two hundred and seventy seven patients were admitted on either Monday or Tuesday during August and September, 1989. One hundred thirty eight patients were randomly selected using the process described above. Of this fiqure ninety-three patients were rejected for the following reasons:

27 - discharged prior to the interview date.

19 - unable to obtain the physician´s permission to interview due to unavailability of the physician or the physician´s assessment that the patient´s was too ill to be interviewed.

8 - unable to obtain the nurses permission because patient was too sick, confused or medicated the day of the interview.

12 - were under the age of 18.

12 - were admitted to an ICU and therefore were critically ill.

8 - were psychiatric admissions.

1 - had a language barrier.

6 - refused to participate in the study.

Three of the patients had a family member present during one or both of the interviews. In incidences where the family member was present and the researcher felt they influenced or helped to clarify the meaning of the patient's experiences, their comments are included in the patient's story. In each of these cases, the family members' comments are identified as their own so as not to distort the patient's response to the research questions.

Research Instrument

Qualitative research requires the researcher to be flexible and to allow the interviewee to describe her/his experiences. To maintain maximum flexibility, open ended questions flowed from the immediate context of the patient's description of caring and non-caring experiences. The interview process began with some warm up questions about the reasons for the patient's admission and who the patient is. This was followed by open-end questions about their perceptions of caring and non-caring experiences which she/he has encountered in this hospitalization. The patient was also asked to describe his/her relationship with his/her physician(s) and nurse (s), and to describe encounters which were caring or non-caring. Secondary questions were asked regarding the admission process, experiences during

diagnostic tests and procedures, and their perceptions and feelings during teaching rounds. Specifically, the researcher asked the patients to describe his/her perceptions of the relationship between themselves and the care providers during these encounters; and the ability of the nurse and physician to convey and/or create a caring environment.

Patients who had previous admissions were asked to compare the caring and non-caring experiences of the previous hospitalizations with the present experience. For those patients who were hospitalized five or more years ago, they were asked if they thought the level of caring or non-caring had changed and if so to describe those changes.

The interview questions used as a guide to the interview process are presented in Appendix A. The first interview queried patients about their experiences from both past hospitalizations up to and including this one. The second interview, which took place after discharge from this hospitalization, queried the patient about experiences following the first interview, and about whether there had been any perception changes about this hospitalization now that she/he had been discharged. The same questions were

asked during both interviews and the second interview built upon data obtained in the first interview.

Data Collection Procedure

Data were collected from two interviews with each patient. The first interview took place while the patient was hospitalized. Due to the time limitations of the researcher, only four patients were interviewed in the hospital each week. The follow up interview took place in the patient's home two to eight weeks after the patient was discharged.

Several patients in the sample had multiple admissions to the hospital which delayed the time between the first and second interview, however, it did serve to generate richer data.

Demographic data on each patient were obtained from the medical record and the patient. This data includes the patient's age, sex, race, occupation, education, martial status, family support, route of admission, clinical service for which the patient was admitted, and diagnosis.

The medical record was used as a another data source for the researcher to understand the complexity

of the patient's illness and hospitalization. During the pilot study the researcher was able to obtain from the medical record additional data about the patients' medical backgrounds and social histories.

The purpose of the post hospitalization interview was to review with the patients their descriptions of events which they felt were caring and/or non-caring during their entire hospitalization. This allowed an opportunity for the patients to reflect on these experiences in the safety and comfort of their own homes, away from the stressful environment of the hospital. Data which differed from what was obtained during hospitalization was carefully probed with the patient.

The interviews were tape recorded to capture the patient's words and to aid in the analysis of data. All patients granted permission to tape record the interviews. One patient requested the researcher to shut off the recorder twice during the interview when he was discussing his comparisons of this hospitalization to another hospital. Notes were taken following each interviews to record the researcher's observations and impressions..

Permission to conduct this study was obtained from the Human Subjects Committee, the physician, the primary nurse, and the patient. A copy of the written consent form was given to each patient. Confidentiality of the physician, the patient and the other health care providers was maintained throughout the study. A copy of the patient's consent form may be found in the appendix.

Immediately after the patient was selected the researcher contacted the patient's physician to obtain permission to interview the patient. The primary/associate nurses were asked the day of the interview if the patient was able to tolerate a one to two hour interview. If the nurse stated the patient was able to be interviewed, the researcher sought written permission of the patient.

Data Coding and Analysis

Data were transcribed from the interviews onto a word processor. The researcher analyzed the data by examining the descriptions of caring and non-caring experienced by the patients. The patient's experience of caring and non-caring were categorized into components and/or characteristic of each phenomenon.

Data were examined for patterns which evolved from various patients experience. Attempts were made to establish the relative importance of each component based upon its frequency, order of importance or emphasis placed upon it by the patient, and the influence of the context upon the findings.

The data were also examined to differentiate gender differences in how males and females perceive and experience caring and non-caring in a hospital. Comparisons of similarities and differences among male and female patients were made and attempts were made to determine the significance of these findings, and the influence of the context in creating any differences.

Components of caring or non-caring were identified in anecdotes obtained during the interviews. Anecdotes were compared to determine if patients perceptions of similar experiences were consistent. Each anecdote was examined to determine the relative importance of the experience to the patient. Patterns which emerged from the data were identified and comparisons were made between ancecdotes to determine similarities and differences which may have occurred.

Perception regarding the nurse's and physician's ability to create a caring environment for the patient during admission, diagnostic tests/procedures and teaching rounds were noted with each patient.

Findings were interpreted using previous relevant research when indicated. However, this is limited due to the nature of qualitative research, and the limited research done on this phenomenon.

CHAPTER 4

PRESENTATION OF RESEARCH FINDINGS

Introduction

Indepth interviews were conducted with sixteen patients who were hospitalized in a University Hospital located in New England. As described in chapter three, each patient was interviewed twice from 60 -120 minutes, with the exception of two male patients; one died in the hospital and the second refused the post interview. The interval between the first and second interview ranged from four to eight weeks since four patients were re-admitted following the first interview. This latter group described both hospital experiences during the second interview, thus enriching the data.

The chapter is divided into three sections. The first section is a description of the indepth interview and the researcher´s role in the process. The second section is the demographic data of each patient and a statistical comparison of the sample population´s age distribution, race, martial status, education, employment, and method of admission. The third section is the "patient´s story", and includes information collected in the interviews using many of the patient´s

words to tell the story. A "story" format was chosen for the presentation in order to retain the uniqueness of each case. The stories provide a context for understanding the analysis in Chapter 5. Not all the interview content is presented here, only those comments that are relevant to the research focus will be presented in this chapter.

Indepth Interviews

Qualitative research requires the researcher to be flexible and to allow the interviewee the ability to describe his/her experiences. The researcher formulated questions as it flowed from each patient's experience using an unstructured interview technique. Patients were encouraged to respond in any way they felt comfortable, thereby giving the researcher a better understanding of how the patient viewed his/her role and the role of the physician and the nurse within the context of her/his experience.

Each patient was asked open-ended questions regarding her/his experience of caring and non-caring (Appendix A.). Patients were also asked to give examples which would describe these experiences. Since physicians and nurses are the primary care providers, patients were also asked to describe their relationship

with the physicians (interns, attending, and residents) and nurses and to describe behavior and encounters which exemplified caring and non-caring.

Since the University Hospital may present unique experiences that patients have not had in a community hospital, patients were asked to describe some common experiences. Specifically, a subset of questions was asked regarding their experiences during the admission process, feelings during teaching rounds, and experiences during diagnostic tests. Each patient was asked whether he/she felt the physician and nurse created a caring environment during these processes.

Patients who were previously hospitalized in community hospitals noted differences in medical and nursing practices in the University Hospital. For other patients this was their first admission, so the role of the patient and care provider was a new experience. In each of these cases the researcher probed whether they thought each experience was caring or non-caring. Patients who were hospitalized five or more years before were asked if they noticed any change in the level of caring or non-caring.

Each interview was transcribed onto a word processor and carefully reviewed for similarity, contradictions and differences. Themes identified were categorized to allow the patient's frame of interpretation to be analyzed in a more systematic way. All interviews were blended and reorganized into different categories.

Demographic Data

Demographic data of patients in this study are presented in Appendix B. An equal number of males (8) and females (8) are represented in this sample. Forty-four % (7) were retired; thirty-eight % (6) were unemployed, and present illness was the cause of unemployment for eighty-three % (5) of them.

Ninety-four % (15) of the sample were Caucasian and one was a Hispanic female. Data, therefore, represents a bias toward Caucasian male's and female's perceptions of caring and non-caring experiences. Two other minority patients were randomly selected, but rejected because one male patient was too heavily medicated to participate in the interview process and a female patient refused to participate in the study.

Figure 1 depicts the age distribution of the sample. Fifty-six % (6) of the patients were over fifty years of age twenty-five % (4) were between the ages of 60-67; and another twenty-five % (4) were between the ages of 19-26. The ages ranged between 19-84 years.

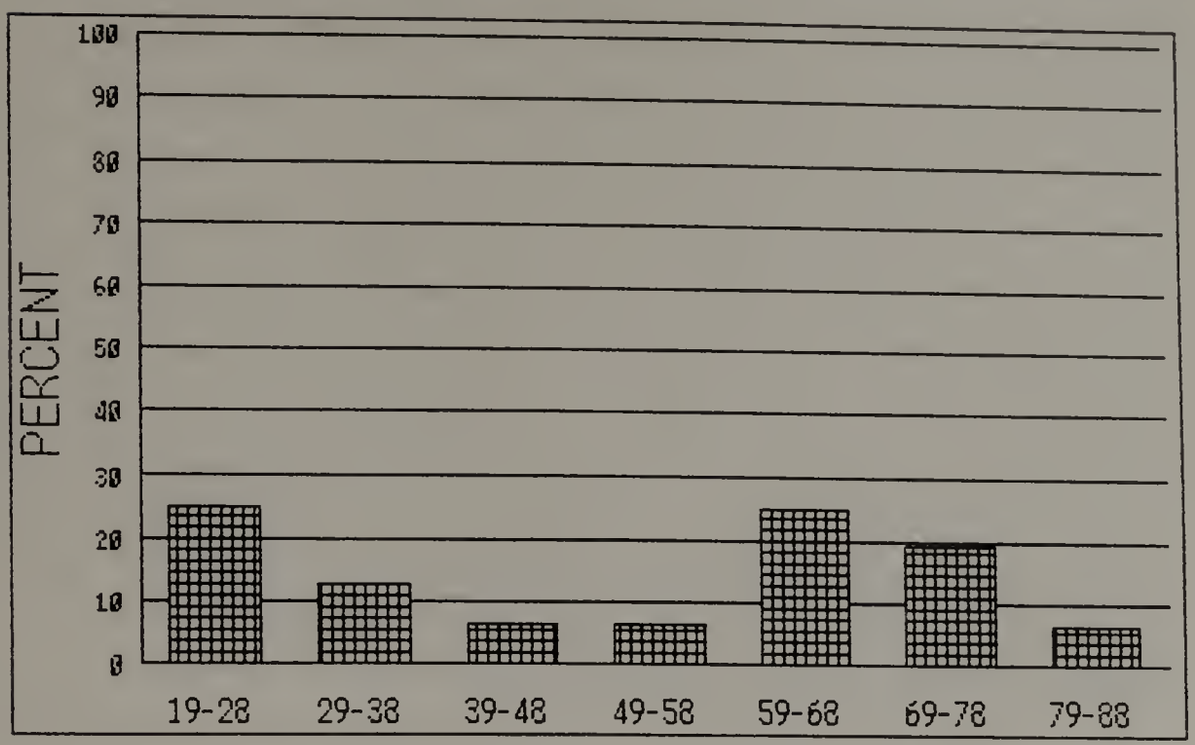

Figure 1 : Age Distribution of the Sample

Of the total population fifty-six % (9) were married and living with a spouse. Another female patient has been in a common law relationship for the past fifteen years. Thirty eight % (6) were single, of which three were the result of a divorce. Two female oncology patients were single parents with school age children at home.

Figure 2 shows patients were admitted for three primary diagnosis: cancer, thirty- eight % (6); elective surgical admissions, thirty-one % (5); and trauma, twenty-five % (4). One patient was admitted for a chronic medical condition.

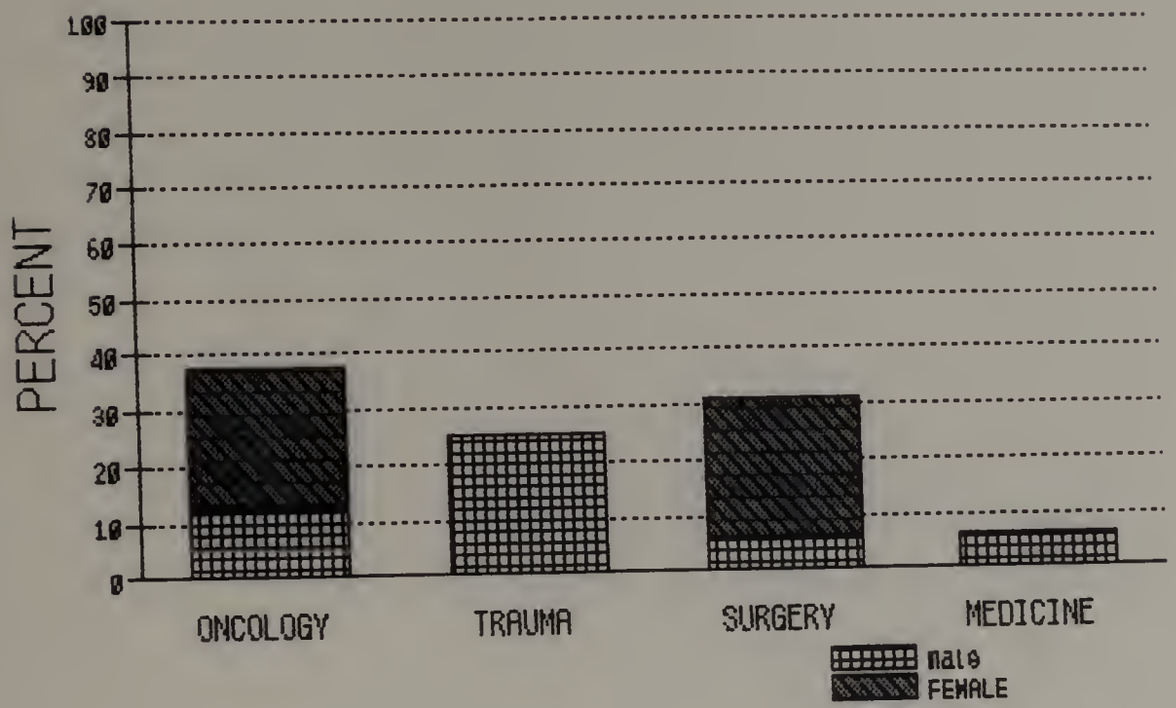

Figure 2 : Clinical Services

Thirteen % (2) lived alone. Another thirteen % (2) returned to their parent's home following their recent trauma injury because of an inability to work.

Figure three shows forty-four % (7) were admitted through the emergency room. Twenty-five % (4) were

urgent admissions from the ambulatory clinic, and thirty-one % (5) were elective surgical admissions.

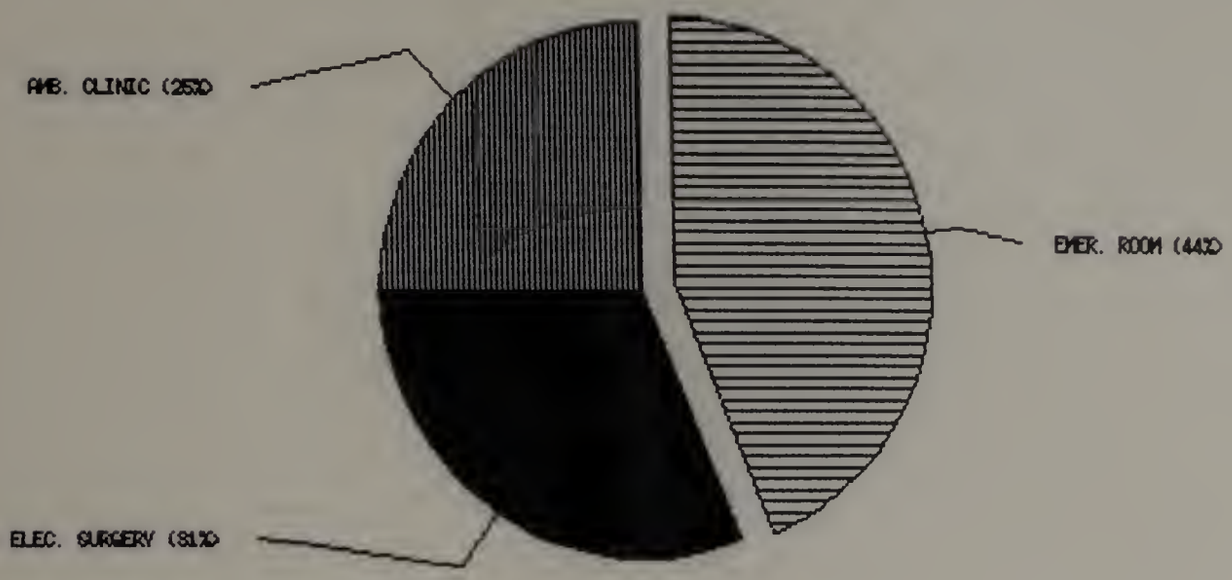

Figure 3 : Type of Admission

Forty-four % (7) received post high school education; but of the total figure thirty-one % (5) were college graduates. One patient was a LPN and another retired patient was presently enrolled in college courses.

The Patient´s Story

The patient´s experience of caring and non-caring is presented as individual case studies or "stories". Seventeen subheadings are used to highlight the themes and concepts which are common treads that cut across

all patients. Theses themes are: 1) A caring experience is .... 2) A non-caring experience is .... 3) My relationship with my doctor(s) is ..... 4) My relationship with my nurse(s) is .... 5) Nurses are caring when they...6) Nurses are non-caring when they .... 7) Physicians are caring when they .... 8) Physicians are non-caring when they.... 9) When I was admitted I felt.... 10) My experiences during diagnostic tests were .... 11) I felt .... during teaching rounds 12) Compared to my experiences in a community hospital .... 13) I´ve noticed ..... changes in caring over the years 14) Changes I´d like to see in a hospital to make it more caring are.... 15) After I was discharged .... 16) My reflections on caring (non-caring) I received in the hospital .... 17) Changes I´d like to see occur in the hospital now that I am home....

In analyzing the data, the researcher found that each patient had his/her own story which didn´t always flow in a neat and orderly manner. In order to present the data so the reader could understand the patient´s experiences, the data was reorganized into the seventeen themes or categories. The stories are presented exactly as spoken, and no attempt was made to correct grammar syntex, or sentence structure. To

protect the confidentiality of patients, doctors, and nurses, each was given a pseudonym. All of the following stories provide a context for understanding the analysis in Chapter 5. The following stories do not include all of the patients data, but only that data determined to be relevant to the research questions.

Story #1 : "I Wanted to Curl Up into a Ball and Disappear"

Marie is a 29 year old Hispanic female who is a single parent with three boys ages, 9, 10 and 11. She was born in North Carolina and moved to New England when she was only three years old. She recently broke up with her boyfriend who is the father of the three children. She had been homeless until recently when she found an apartment for herself and her children with the help of social agencies.

The medical record reveals a history of abusive behavior toward the patient from the boyfriend. Marie admits to occasional alchol and states she "has not taken coke for the past six months". Marie had a melanoma removed from her leg a year ago and has been closely followed by Dr. G., an oncologist at the University Hospital. The admission diagnosis is to rule

out a metastic melanoma, infectious process (elevated WBC) or diverticulis. She has lost 18 pounds in 10 days.

Marie has established a warm relationship with her son´s neurologist and discusses with him her own medical problems. Her son has a history of a neromuscular disorder which was diagnosed several years ago. He is being seen in the University Clinic by Dr. M. and is enrolled in a handicap school in town. The other two children are healthy and enrolled in the public school system.

I FIRST CAME TO THE HOSPITAL .....

"I was referred to hospital by my son´s doctor because of weight lost and nausea, vomiting and diarrhea that I´ve had for the past month. I´ve lost 18 lb. in 10 days and I´m starving to death...could be my nerves---but I just needed to..... very good people here, they´re fantastic."

"My son has a chronic neuromuscular disorder so I moved up here and started to bring him here. Last year I had a problem and I went to the doctor and I had skin cancer on my leg. So I´ve been coming here for that because they were good people".

A CARING EXPERIENCE IS .....

"The people are fantastic. The nurses are really nice. The only thing is if you don´t feel good, an you have 10 people around you, and everytime you get to sleep, they wake you up. That is the only thing".

"The residents ask the same questions over and over again so I´m able to anticipate what they are going to ask me. I really don´t mind it. It´s kinda annoying because I don´t feel good you know, whereas

I´m irritable, getting grouchy, depressed, and .... want to get it over with".

COMPARED TO MY EXPERIENCE IN A COMMUNITY HOSPITAL .....

"....I´m from the south, and down there the hospital in my home town wasn´t really like a teaching hospital. They might have rounds in the morning, you know what I´m saying, but that´s it. Other than that you see your normal doctor. But around here it´s different, all the time coming in and asking questions, same cast over and over. You get to where you know them by heart".

MY RELATIONSHIP WITH MY DOCTOR(S) IS .....

"Always been good people. If I had a problem the doctor, even if its not medical, they don´t push you out. They act like they really care. I´ve been dealing with the Medical Center for 9 years now with my son. Any problems I had I could bring it to my son´s Neurologist, he´d help me with them..... it´s not that outside the office you´re a stranger. Anything you need he helps. I can discuss personal things and he´d help me. He´s a friend."

"He (son´s neurologist) got me in here. My son had an appointment and he was the one who told me to tell my physician and get something done. He´s not even my doctor but he acts like he really cares. He´s a friend."

"They (doctors) have always been good people. They are very understanding. The doctors I have, like if I have a problem, even if it´s not ... I think I could talk to them. It´s not like they just push you off or whatever. They act like they really care. That´s the way I feel about it. If it wasn´t I wouldn´t be coming here. Any problem I used to have I could go to my son´s neurologist. He would help me with my problems. Like I was homeless at one time. He helped me with that. It´s not like outside of the office you´re a strange. Anytime you need his help..... He´s like a friend".

(What about your relationship with Dr. G., your oncologist, what is that like?)

"He´s great. He is understanding. I can talk to him. He makes me feel like a person instead of a patient".

WHEN I WAS ADMITTED I FELT .....

" Well, I talked to my doctor (oncologist) on the telephone and he was concerned about me and he told me to arrange for a baby sitter and to come to the emergency room and that he would notify the emergency room and that he would have me admitted. You know, because I had went to him a couple of months ago complaining too and so he said he wanted to admit me to do test to find out. You know to see if they could find out if there was anything wrong.... find out what's causing this."

"It's a long wait. I got here at 4:30 that evening and I didn't get into my room until 10:30 at night. I had to wait so long because they had a lot of emergencies coming in and I wasn't really an emergency".

"There was one incident..... the admitting doctor was down there (emergency room) and the nurse keep knocking on the door saying the room was ready and the doctor was trying to do the examination. She told him, you know, you're not suppose to do this down here. You need to do this examination upstairs. It made me feel bad. If they are going to have a confrontation like that, at least call the doctor to the side and tell him this".

MY RELATIONSHIP WITH MY NURSE(S) IS .....

"They are so nice. they are just like whenever you need anything they are there..... They don't make you feel like you are imposing on them and even if I don't..., like I haven't really bothered with any of them since I've been here since I don't feel good myself. I don't really bother with them much, but they will still come in and check up on me .... make sure there's nothing I need. They are so nice here. It makes you not feel quite as bad about being here".

COMPARED TO MY EXPERIENCE IN A COMMUNITY HOSPITAL .....

"When I was in a community hospital in the south, there you had to ring and ask for things. Here they act like they care, there is no comparison. The others were snooty... acted like they were better than I was. Here they act like they are doing a job they enjoy, rather than doing a job because it is a job."

I FELT .... DURING TEACHING ROUNDS.

"They want to learn about you; they want to learn about your background, your problems, you know, if there is something that they can do to help you with your stay here. And then they have like five students come in and only one of them talks to you, and then it´s like you do this for me. How does this feel. You really can´t explain to them how you feel. Like the older doctors you can say, well I just feel blah. You say that to the newer doctors and they like, exactly what does that mean? But they will learn, they are new".

"I feel embarrassed and awkward. If you come here, have to be understanding. They come around both in the morning and afternoon. It would be better if there were only one or two physician. Its easier to speak to one or two doctors than 6 or 8. When I was in the hospital in the South the doctors made rounds once in the morning other than that you saw your regular doctor."

"When I was on the surgical floor it was better because there were less rounds and my surgeon was present at the rounds... I felt better having my doctor there because I knew he was there for my best interest".

"It´s better when they come in on a one to one basis with the person, it´s more personal".

CHANGES I"D LIKE TO SEE IN THE HOSPITAL TO MAKE IT MORE CARING.....

"It still, however, is very boring. I´m scared to leave room because you´re afraid they´ll do some tests and they try to fit you in....If I was to change anything, I´d tell patient when you need to be in your room ....at such and such time because your going for tests, rather than lay around waiting."

"As for the residents some are nice and some aren´t..... They have to learn their bedside manner. They aren´t rude, but they´re difference. You can tell the difference with the new residents physician and the ones that are going to school here and the older ones. The older ones are more understanding .....you know they´re got more compassion. With the newer ones its..... like basically text book questions they ask you. .... They are more interested in learning what´s wrong with the patient instead of the patient and how the patient feels about what´s going on".

(How does that make you feel?)

"It make you want to just curl up in a ball and disappear. But they got to learn but at the same time they could be a little more compassionate about their learning".

"If I was the teacher I would tell them, get to know the patient first before you...., then get to know a little bit more about them. Then start the learning process, you know, your questions, stuff like that, but don´t be cold about it. Try to be understanding about it".

The second interview took place in Marie´s apartment. She lives in a first floor flat in the city. Her handicapped son was with her sitting in a wheelchair watching TV. She was making him some popcorn. He was not very talkative, just quietly watching what was going on.

Marie appeared to be uncomfortable at first as if the interview was an intrusion into her home. As the interview went on, she began to relax.

The boy had a large scrape on the side of his face. Marie comments on how bad he looks and that the scrape was caused by his brother when the two were fighting last night.

AFTER I WAS DISCHARGED ------

"I was in the hospital for five days. I´m still going for tests, but it´s not as bad, like if I eat a little bit at a time I can keep it down, but if I eat a

big meal it won't stay down. They are still doing tests and the one test that really might have told them something, a liquid that I had to swallow.... it bad enough when you're feeling good much less....."

MY REFLECTIONS ON CARING .....

"I don't have any complaints. They made you feel comfortable. They made you feel like they cared about you. I don't have any complaints about it".

"Dr. G. he's great. He's understanding. I can talk to him. He makes me feel like a person instead of a patient. He has seen the worst and he can understand how people feel when they find out they have cancer. Everytime I get sick I get scared, and he understands that".

(So a person feels different than a patient? Could you describe what you mean by a patient?)

"A patient type is when they come in for rounds, you're a patient, you are something for them to learn about, they want to learn from you. A person, they come in, sit down, they talk to you, you can tell them personal problems. If you feel like crying you can cry in front of them and not feel bad for crying".

"With a patient you feel like you got to be strong, you've got to answer their questions and you can't break down and cry if you want to cry. It's just a completely different feeling."

(Does the patient learn this role? Like you are expected to be strong and answer all their questions?)

"Basically when you come in you tell yourself before you come in here, now this is a teaching hospital. There's going to be a lot of people coming in; there is going to be a lot of tests and stuff, basically answer the questions, do what they want you to do. You can't really get personal with them because it's like you might have a different group tomorrow".

"You don't want to break down and cry in front of strangers, that you're a nervous wreck, that you're depressed and all this. And then you might not ever see these people again".

"It's not a personal thing. It's not like people are going to be there all the time when you need them.

They are basically there to learn medically what is wrong with you, not physically, they are there to learn medicine".

"The nurses were wonderful. Just their attitude alone. Just their attitude made you feel like they care. You feel like you are bothering them, but they assure you that they are not... that they´re there to help you and stuff."

"I didn´t see the doctors much except in the morning when they came in to probe and poke. Most of my dealings were with the nurses... so if I had a question I´d ask her and she´d ask the doctor and let me know".

"Mostly the resident I deal with. I have a strong relationship with Dr. G. If I have a problem I can call him. Like I said they all caring it´s just that the residents its more like they´re there to learn. You gotta get use to it".

CHANGES I´D LIKE TO SEE OCCUR IN THE HOSPITAL NOW THAT I AM HOME.....

"No. The only thing I would change is when the nurses come in when you are sleeping at night. They would come in and wake you up to take your vital signs.

"I´d recommend the hospital to all my friends".

Story #2 : "It´s Been a Really Long Time"

Betty, a 37 year old white female, developed asthma during the first trimester of her pregnancy. She was put on prednisone to relieve her severe asthmatic condition. At the fifth month of the pregnancy, the doctor recommended an abortion because he felt the fetus was compromised by the steroid treatments. This was unacceptable to Betty´s husband although it would have been acceptable to Betty at the time. Four months

later she gave birth to a healthy baby girl. Betty is grateful that her husband insisted that the baby not be aborted. This child is her only child and is presently thirteen years old.

The steroid therapy proved to be a more serious threat to Betty's health rather than the child. She developed avascular necrosis of the tulus which was secondary to the high dose of steroids. In the past five years, Betty has had six surgical procedures due to tular dome fractures of the right ankle and revascularization of bone grafts. In spite of all these surgical interventions, Betty is left with chronic pain and limited mobility.

Betty is a former LPN and has not worked for the past five years due to her chronic condition. She lives on the second floor of a two story house. Her parents own the home and lives on the first floor.

I FIRST CAME TO THE HOSPITAL .....

"I never got rid of the asthma after I got it. I was admitted a lot of time to the ICU on a respirator. What I don't think the doctors realized looking back in retrospect, I didn't either, they were giving me massive dosages of prednisone. I was coming home on 100 mg. a day and I could never get down below 60, anything below 60 I would get asthma really bad and end up in the hospital. But as time went on my leg started

to hurt me. But it was funny because I don't remember falling or banging it, there was no bruises or swelling".

"So I waited about two months and saw my family physician and he said ... so for about six months he found out that I had ... and it was from the steriod. Four times the ankle shattered and I wasn't even doing anything. When the other leg started to go they talked to me about vascularized graft.... take a bone out of my other leg and put it in there and then do a skin graft".

"When I went back To Dr. M., what happen was I fractured it... he went in and he told me yesterday that the cartilage was ripped on one side, too, so that caused me a lot of pain. He thought that it looks good.....so I'm happy about that. It's going to be a while before I walk on it, but after all that I don't care if its forever. I just don't want a fusion done".

PHYSICIANS ARE NON-CARING WHEN .....

"The first time I came to the hospital I went to see Dr. A. for my leg. He told me when I couldn't walk on it anymore to come back ..... I don't have too much respect for him. Not much of a bedside manner. He said this is what happens when people get elderly, is to fuse it, and you are too young to fuse it, so when you can't walk then come back and see me. I had my father with me that day and I went home and was telling my husband, he said I don't believe it. He didn't give a damn what happen to me. So anyway I called Dr. M."

COMPARED TO MY EXPERIENCE IN A COMMUNITY HOSPITAL....

"Primary nursing is better because one nurse knows you. At Community West Hospital where I used to work they do team nursing. The nurse is unable to personalize care in the same degree as in a hospital where primary nursing is practiced because the focus of team nursing is upon group of nurses completing various aspects of care. In primary nursing the same nurse takes care of the patient from the day of admission to the day of discharge. She is responsible for the plan and coordination of all aspects of nursing care. This is a better way to care for the patient because both the nurse and the patient are able to establish a relationship and understanding about each other. This is better. That's what is so different about here and there."

A NON-CARING EXPERIENCE .....

"An incident occurred the other day, Thursday, after I had surgery... they brought me two dinner trays one for this lady (roommate) who wasn´t back yet and one for me. So she (nurse) called down and got me a sandwich. This guy came up and I was feeling groggy... big knot on your neck... when I look back on it ... so he started rubbing my neck and the next thing I knew he´s bent over the bed trying to kiss me. I´m not kidding. His name is Mike and he´s 19 years old... So he says, ´what is it, just the age difference ?´ I said I´m a married woman. That´s no way to be acting. The guy that delivers the tray. From the bed you can´t see out there (corridor). He really scared me. I picked up the phone and was calling my husband, and he came back in.... he said,´ Who are you calling ...?´ I put the phone down... That was the main reason, you know..."

(Did you ever report this to your nurse or doctor?)

"I wasn´t going to but the more I thought about it I got scared .... I worried about it all day. I thought he was just a screwed up 19 year old. Then I felt he might try this with another patient, so I reported it to the charge nurse."

MY RELATIONSHIP WITH MY DOCTOR(S) IS .....

"Dr. M. (Orthopedic surgeon) is a concerned and caring doctor. He watches the medication.... he´s easy to talk to. He called my husband right after the surgery . He always returns calls. He does everything to make you comfortable. He even came in at 5:30 P.M. just to tell me he would not be in on Saturday...just to tell me someone else would be covering. He checked me to see if I had pain...reasured me the pain clinic staff would be around to regulate pain medication."

"Dr. M. still explains things as if I were a lay person...not condescending. Even my husband is able to understand.....I just hope after 5 years he doesn´t change...so many do when their practices get so busy. They don´t have time to talk and see patients."

"Dr. N. (another Orthopedic surgeon) gave me his home phone number. I never called him...felt funny calling him. But one day Dr. N. asked me if I would be part of their grand rounds. I said sure but what do I do. Well all I did was go the ampitheater and they presented my case. The medical student asked me

questions. One of them asked me if I planned on suing my medical physician. I thought that was funny. I told him I had no intention of suing him".

"I know he should have been watching my medication closer but ..... what was the purpose"?

(Could you clarify what you mean by that?)

"Well he was caring and concerned about my daughter, how could I"?

I FELT .... DURING TEACHING ROUNDS.

"Two or more house staff make rounds daily. I knows what to expect and understands their language. I felt comfortable discussing my condition with them and asking questions. I found the rounds helpful because I got to know what their game plan was for that day".

MY RELATIONSHIP WITH MY NURSE(S) IS .....

"I feel more comfortable..... nurse knows what medications I"m taking. At Community West they wouldn´t want to know.....cold. When I was in ICU I felt like I was a number. I think it makes a big difference. If you don´t like the care, it just increases the stress (of the patient) when you are already burdened".

NURSES ARE CARING WHEN THEY .....

"Sheila, my primary nurse, she is so thoughtful. She offered to was my hair today. Now she doesn´t have to do that. I know she is very busy with other things. It is the simple things that mean so much to patients. I usually washed my own hair daily at home, and it feels crummy that it hasn´t been washed in days".

"Here the nurses ask you when you want to wash up...not routine that everyone must have a bath in the morning".

"The nurse put lambs wool on the bed. I didn´t ask for it".

"The other thing I like about this floor is that the nurses will answer the patients´ lights that aren´t their own patient´s. They have a good sense of team spirit..... A caring nurse tries harder".

NURSES ARE NON-CARING WHEN THEY .....

"Last night I was miserable. I couldn't regulate my pain medication. So I called the nurse for assistance. She told me she'll ask the pain clinic to check the PCA program. (The PCA is a computerized control device that regulates the pain medication in the mg's ordered by the physician.) Finally when I didn't hear from anyone after I called five times, and no one from the pain clinic come up..... I find out that the nurse didn't call the pain clinic because someone thought it was closed. But she never called herself or called the doctor or even told me."

MY EXPERIENCE DURING DIAGNOSTIC TESTS WERE .....

"Angiography was the worst. I psyched myself up ...I was so afraid of test. The doctor gave me valium. They were playing WROR, the oldies,... he asked me what kinda music I liked. He was a caring person"

"The test itself was scary. Worst for me because I know too much... it increased my anxiety."

"One time a doctor refused to treat me because I was smoking. He told me to go home and when I'd made up my mind to quit, come back and he'll treat me. Although I was annoyed by his behavior, I did go home and quit smoking for three weeks and then returns. My husband smokes in the bathroom so he wouldn't smoke in front of me. He wants me to quit smoking too. In retrospect I thinks this physician handle me right because I did quit smoking and I probably wouldn't otherwise".

I"VE NOTICED ... CHANGES IN CARING OVER THE YEARS.

"None really. Only the food. I dislike having the same menu for dinner and supper, and think the quality of the food is poor".

CHANGES I"D LIKE TO SEE IN THE HOSPITAL TO MAKE IT MORE CARING.....

"None".

The second interview took place in Betty's backyard a month after her discharge. She appeared depressed and concerned that the surgery had not

corrected her problems and that she would need a fusion. Her leg is still in a cast and she hobbles around on crutches.

AFTER I WAS DISCHARGED .....

"I´m getting tied of the whole thing. I thought by now it would be healed. I don´t want to have to have it fused. I go back in 6 weeks. I hope by then it starts to show some healing".

MY REFLECTIONS ON NON-CARING .....

"The only thing I noticed was that the lady (roommate) that was in with me, she was constantly calling the nurses for stuff and it got to the point that they were kind of disgusted with her. They would tell her you are going to have to wait or whatever, but I didn´t experience any of that".

(As an observer you felt that she was not treated with dignity?)

"Yes, some of them were. They got her pain medication right away. If she was using the bedpan they got that, but the little stuff in between...."

MY REFLECTIONS ON CARING .....

"My primary care nurse Sheila, she was the best nurse I´ve ever had. Her attitude was different. She was really down to earth too, it wasn´t like ah..... like the day I had a seizure, I´ll tell but please don´t ... she had never seen a seizure before. She said, you scared the shit out of me Betty. I started laughing. It didn´t bother me I´ve had seizures before. She´s really down to earth. She come in and if Mildred (roommate) needed help she´d go over there and help her where some of the other nurses would walk out and say I´ll get your nurse. You can really tell she loves what she is doing. It´s not just a job and you got to get through the day. It really shows".

"I´m not saying the other nurses weren´t good, because they were. I got really good care. But there was just something about Sheila that was different. The other nurse I liked was Trish ...she lost her husband. She was real good to me too. But there was something

about Sheila. Even my husband liked Sheila, and he hates hospitals. She really loves what she ´s doing and you can see it. You really can".

CHANGES I"D LIKE TO SEE OCCUR IN THE HOSPITAL NOW THAT I"M HOME.....

"Do you think this interview would change the food? Really bad".

(Would you change anything else?)

"No".

"I have to wait to see if it will heal. They had me in a cast and pinned me before before I went in but that didn´t heal. They pinned it to the vascularized bone and now it´s just a matter of it healing. He is not going to wait a long time for it to heal. It has been such a long time now, that if it doesn´t take I´ll probably end up getting it fused and that´s the one thing that I don´t want to do. That really scares me. I went through all of this vascularized bone graft ... oh it was painful ... I´m not to crazy about the idea of a fusion. I really dread that. I went through this crazy of bone grafts to try to avoid that. I´m not too happy about that thought of a fusion. It´s been 5 years since I started this process.... it´s been a really long time".

Story #3 : "I Didn´t Know What to Expect"

Keith is a 22 year old, white, single, male who was drunk at the time of his accident. He and some of his friends were out partying when they came across an accident on the highway. Out of curiosity, he got out of the car to watch what was happening when he lost his balance and fell 30 feet from a bridge to the pavement below, landing on his feet.

He sustained a traumatic fracture of the right tibia and a fracture of the metatarsal in his left foot. The fractures required an open reduction to repair the bone. A cast was applied in surgery. Since his hospitalization he has had three surgical procedures.

Keith works in construction and had recently returned to his home state. The accident caused him to lose his new job since he lacked seniority, and his injury was severe enough that he would not be able to work in construction for at least a year. Now unemployed he returns to his parent home post surgery.

I FIRST CAME TO THE HOSPITAL .....

"I fell from a bridge ... I dropped off some thing up on the highway.... and some guy skidded so I went to check it out and there was a guy in the woods so I started to run down there and there was a bridge... one lane going this way and one lane going the other way, and there was a big space... I was running and I took the wrong step and fell to the road below".

"My friends called an ambulance and they tried to keep me awake and here I am".

WHEN I WAS ADMITTED I FELT .....

"Kinda scary. I was brought to the emergency room....a whole lot of people tugging on the railing..my knee, my arms...I was in a lot of pain. Still have broken bones. They took me up to surgery to fix my leg. I'm going again next Thursday ... cartilage or something...., cut a piece of bone out of my hip...and they put a steel rod in my leg the last time".

"It´s all kinda fuzzy. I remember the ambulance ride... I talked to the driver... I guess it bothered the ambulance driver. I remember him because he was some kinda hot shot driver the way he was driving. He was driving crazy and each bump was killing me".

(So how do you feel about being in the hospital?)

"There´s nothing I can do . I just had seven stitches in my knee and I was out of work for three weeks where I gashed it on the guardrail jumping over the fence".

"I´m still in a lot of pain. I take one sleeping pill at night. For a while I didn´t even know I had them and didn´t take any at all and didn´t sleep for days".

"I heard a guy ask for one and I said hey, I want one too. He (doctor) said ok, we´ll give you one, just ask".

MY RELATIONSHIP WITH MY NURSE(S) IS .....

"The nurses are good. I was in another room and the guys were banging (construction in the next room) away, they started at 7 in the morning and ended at 5 banging on the other side of the wall. It´s quieter over here. When one guy left (this room) they put me in here. The nurse even moved me next to the window after my roommate left".

"They (nurses) do their job. Know what they are doing. I´m still alive. I don´t see anything they´re doing wrong. They bring water and stuff. They joke and kid around."

"Sometime you wait for a while but they are probably doing something else".

NURSES ARE CARING WHEN ....

"They check on you, make sure you are all-right. Do what they are suppose to do when they come by. They should be there in case you need something. Just do their job".

NURSES ARE NON-CARING WHEN ....

"There was one nurse who said she was going to get me some pain medication and she never came back. She

said she'd be back but she never did and I was in pain. She doesn't care about her job ....just getting it over with."

MY RELATIONSHIP WITH MY DOCTOR(S) IS ....

"Dr. M. is my doctor....I don't really know him. He's a nice guy. He gets you better. I don't know... He is a comfortable guy to talk to. Knows his stuff".

I FELT .... DURING TEACHING ROUNDS.

"Didn't know what to expect. At first it was a pain in the neck, and after a while .....come in take blood, ask how you are doing, tell you what's going on for the day".

(Do you feel a part of the discussion or do you feel separate?)

"Oh yes, after a while ... good questions, how are you doing? It got more easy as I got use to it".

MY EXPERIENCE DURING DIAGNOSTIC TEST .....

"It was nice. You got sick of looking at these four walls. You get to see the hospital when they take you by the stretcher. Didn't bother me at all".

"When I went for a CAT SCAN I didn't know what to expect. It was rather scary at first. The staff were o-k. They knew what they were doing but they didn't tell me much. All I remember was being in that room alone and not knowing what to expect."

"The Operating Room..... it's scary each time The staff are good, they try and prepare you but it's still scary each time".

CHANGES I"D LIKE TO SEE IN THE HOSPITAL TO MAKE IT MORE CARING...

"Food- It doesn't taste good..... The nurses could come around a little more".

The second interview took place in Keith' s parents home. He has been home for a month. His cast

was just removed a few days ago and a brace is now in place on his right leg. A small boot has been made for his left foot. He has learned to manipulate around on stretchers and is anxious to return to his normal life. He insists on driving his car in spite of his cast and brace.

The doctor told him he cannot return to his construction job for at least a year because of the damage to his bone and leg muscles. He must now find another job and doesn´t know quite where to begin. His foot is in a walking cast so he has just begun the long haul of physical therapy.

AFTER I WAS DISCHARGED .....

"This is worst than the hospital. The first day I came home, then they put the cast on me too tight and cut the circulation off my toes, so I had to go back and they made it looser. I told them when they put it on that it was too tight .. in the hospital".

"It´s good to be out of the hospital. But I can´t do nothing. I have to make my own lunch. I can move around pretty good..... I can drive my car but I´m not suppose to. I´m concerned about my foot it looks distorted to me".

MY REFLECTIONS ON CARING .....

"My experience was good".

(What made it good?)

"The doctors were good. If you had a question they would tell you. I asked about it and he told me all about it".

(When I ask you to describe caring does that create an image of a nurse or a doctor or both?)

"A doctor more or less".

MY REFLECTIONS ON NON-CARING ....

"Only as far as the ER, I mean she was going to get something and it took her three hours".

Story # 4 : "So That Is What We Did to Correct the Problem"

Edward has had multiple admissions to the hospital for metastatic cancer of the lung. The medical record shows a 70 year old male with Stage II adrenocarcinoma of the right upper lung and a history of ETHOL abuse and GI bleeding.

During this admission they found pathological fractures of the femur with metastasis to the brain. Throughout this interview Edward refers to his cancer as "an infection".

He sold his insurance company three years prior and was doing consultant work up to his recent hospitalization. He is a well know leader in the community and was on the local Board of Trustree of a community hospital. During the interview he makes several references to his trustee status and involvement in other community organizations.

Edward likes to be in charge and this comes across during the interview. He and his wife had two children both of whom are college graduates. His son lives in the area and his daughter is in investments in the Mid West.

I FIRST CAME TO THE HOSPITAL .....

"So what happen was I had my lobectomy done, I had my radiation treatments, I had two of those, then I went to Florida for a week; then I came back, and then they found on another x-ray another lung spot so then I came in and got that removed. Actually it turned out so painful that I had to get a total hip and femur replacement. Somewhere along the line during that whole thing, I had a ruptured stomach so I was bleeding internally. Oh, I had a nice time!"

"The key is Dr. K. (Oncologist) and she is the one who arranges for the radiation. Now I've got to get back next week when I get out of here and get some more radiation for my hip. Unfortunately they found some traces of infection in my head. So these have to be taken care of. To what extent anything can be improved or put on hold, we don't know. So that's the story."

"Tuesday afternoon and Wednesday were extremely painful, so they put me on morphine and I had a reaction to that. I got completely disorientated. They had to take me off that and put me in a piece of restraining gear. So then, we finally got the pain correction regulated".

"When I went back in for the second operation this week, the first one was done last week, and they said what do you want to do? And I said I want the contraption (restraints) put back on. I don't want to be responsible for anyone being injured or hurt or anything like that. But everyone has been beautiful. I slept fine last night".

A CARING EXPERIENCE IS .....

"With a couple of exceptions, very satisfied. The training and the professional attitudes, the procedures, and everything...."

(Requests me to shut off the the tape recorder while he compares this hospital to his own community hospital).

"Whole approach is different. Whole professional medical approach to health care, except for stinking kitchen, is better. But I´m a poor finicky eater"

(Have you had any experience which you felt was non-caring?)

"None. May have been different procedures, personal preference for procedures, but that was personal. They had difference of opinion only because they were so dedicated".

"I had very good rapport with the people who care for me".

WHEN I WAS ADMITTED I FELT .....

"I was admitted through the emergency room because I couldn´t tolerate the pain. I was admitted directed to this floor....This is the cancer floor.... Oncology."

"Actually Dr. K. had a representative there in the the emergency room when I came in so I was admitted and came to this room".

MY RELATIONSHIP WITH MY NURSE(S) IS .....

"I can say that some of these girls, technicians. whatever you call them, at the end of the day when they were pretty frazzled, I would snap at them and once in a while one would snap back at me, kid me. They would say oops, I´m sorry, I apologize".

(So you didn´t perceive that the person who snapped back as someone who didn´t care about you as a person? They were just responding to your behavior.)

"Yes.....They are very caring, treats you as a person. Let me be involved in my care..... they treat me as a person, honest, joshing back and forth, competent, knowledgeable. I feel comfortable with them. I hate to say this but they are better than the nurse at my hospital ... better educated, more competent, but don´t tell them I said that".

COMPARED TO MY EXPERIENCE IN A COMMUNITY HOSPITAL.....

"There is always a lead doctor, 2 residents, 2 interns and 2-3 students. In this teaching hospital as far as I know, of course, the teaching Fellows, these are the ones doing the instructional work, they have to repeat everything to each student who then has to repeat it back".

MY RELATIONSHIP WITH MY DOCTOR(S) IS .....

"Being a bit of a chauvinist, I didn't know quite what to think at the time, having a female doctor and all, and I felt a couple of times I was unnecessarily put off, but as it turned out on investigations I was not".

(You got put off by her?)

"Well by some of the people in her department."

(Not necessarily her?)

"Oh no. Any time we had any kind of a problem or stuff I wanted to know and she wasn't around, or my wife wanted to talk to her, she would call the house. She had our phone number. ..very attentive, very good".

(Would you describe her as a caring physician?)

"Yes, very. She loses a lot of her patients. It's just the nature of her specialty".

DOCTORS ARE CARING WHEN THEY ....

"Instills confidence. Explains in extreme details. I like that. I know what is going to happen. Like we don't know how many spots in your hip have perhaps been infected. She is very quick. Forth right, direct, honest, doesn't hide information and answers questions. You have to have confidence in an individual like that".

"I appreciate her honesty. I couldn't operate any other way and I've been through many disappointments in life where you loose confidence in people and its disheartening. In many incidence, it is embarassment or dangerous to someone else. Overall honesty is good....she is definitely that. ".

"The interns and residents are well trained, conscientious, good coordination...see it myself"

I FELT .... DURING TEACHING ROUNDS.

"The teaching rounds changed a little since I´ve been here because I"ve been zinging them so badly. Nasty enough to insist on it"

"Hell its my life not their life"

(Do you think the tendency is to exclude patients?)

"Well, I just know what I´ve been through".

MY EXPERIENCE DURING DIAGNOSTIC TEST WERE .....

"I went to CAT SCAN at 11:30 at night and they must have regretted seeing me come in because I threw up all over them, and I couldn´t be more pleased. The procedure was all wrong. I tried to tell them but they looked at me like who are you to tell them".

"For the most part the diagnostic test were handled with care. Staff explained the procedures in detail. There were no surprises".

CHANGES I´D LIKE TO SEE IN THE HOSPITAL TO MAKE IT MORE CARING .....

"I´d like to hold off a week so I can reflect on what I´ve said. Right now I wouldn´t change a thing that the doctors or nurses do".

The second interview was unable to obtain as patient died in the hospital.

Story #5 : "I´m Afraid to Ask Questions"

Marion, a 69 year old female, has lived with a male companion for the past fifteen years. She had eight children, but only five of them are alive. Her husband adandoned her and her children shortly after the birth of their last child.

Will, her male companion, opened his home to Marion, her daughter and grandaughter. Prior to that time she was dependent upon welfare to support her family, and lived in a small apartment. She worked as an unskilled laborer trying to supplement her income but found this was too difficult with the sole responsibility of bringing up a family.

Shortly after the birth of her last child she developed a prolapsed uterus. Feeling she could not afford to pay for the surgery or leave her new baby and children alone, she decided not to have the surgery. This was the first time she ever dared to disobey a doctor. "I never did that before". She has lived with this condition for the past thirty years.

Marion was admitted to the hospital because of bleeding which recently occurred from a complete prolapse of the uterus. A vaginal hysterectomy and an anterior and posterior repair of a cystocele were performed as an elective surgical procedure.

I FIRST CAME TO THE HOSPITAL ....

"I woke up one morning and there was blood everywhere, all over, in the toilet, I couldn't turn it off, and I got scared. So I got a towel, got something to put on, woke my daughter up and I said I guess you'd better take me down to the hospital. By the time I got

there it was subsiding. It was almost like a quick hemorrhage and then it stopped".

"They (Emergency Room doctors) told me to see a gynocologist and I only knew one and I really didn't like him. I said I don't have one, I don't go to medical checkups because I can't afford them, so they had me see Dr. G., but I was afraid of him".

"I went to check it out and he said you've gone this far, use your muscles and tighten it back up and you should be all-right. So I was apprehensive. You're got to feel confident in the person that you get. So I called here just to see if they had a medical program for low income people because I was all set to see if they had a program..... maybe they had more research. Because you have in the back of your mind that maybe you've got cancer or something".

"I spoke to Jimmy, the financial counselor, and he referred me to Dr. H. The funny part about it is my daughter knew Dr. H. because she worked at the Center and so she helped me get the first visit. I couldn't get over how helpful Jimmy was."

A CARING EXPERIENCE IS .....

"Everyone has been picture perfect here. Couldn't ask for better care anywhere. They have been absolutely marvelous. The nurses, everybody have been sweet, more than sweet, I'd say perfect. They treat you like you are somebody special. Like they were your best friend. They care so very deeply about their patients. I am going to miss this kinda care when I get home. Everyone was fabulous"

(When you talk about them being fabulous to you, Marion, can you describe what type of behavior they exhibit?)

"They make you feel like part of their family. You feel relaxed and they care. They care so very deeply. From what I've seen everyone of the patients have had this type of care, even from the students that come in".

DOCTORS ARE CARING WHEN .....

"Dr. H. called me personally to tell me I didn't have cancer when the operation was over. He called my daughter and told her. The doctors usually don't make

this personal call themselves which I think is simply out of this world. It counts a lot."

"It makes you think that there are a lot of nice people in this world" (Gets choked up and tries to hold back tears).

NON-CARING EXPERIENCE IS.....

"Not at all, no way . Its been like a little touch of heaven".

(In previous admissions to a hospital have you ever experienced a non-caring experience?)

"Yeah, I had that. My first child was held because the doctor was outside. My baby wasn't ready yet and all of a sudden it came and they held it back until the doctor got there. That was the first and I lost that one and I was young and naive and I didn't know how to push that".

MY RELATIONSHIP WITH MY DOCTOR(S) IS .....

"He (Dr. H.) is very explanatory. Explaining the whole thing right out on the table. He is kind. Everybody loves him. He is quiet. I kid with him and he jokes back. You known that you are getting the best of everything he has to offer."

"I started smoking after my husband left me . I lost weight. I was depressed and had a nervous breakdown. The doctor suggested that I take up smoking as means of relaxation so I did. Now the doctor told me I must give up smoking because of its effect on my health so I did."

(What about your relationship with the residents and interns?)

"Everybody has been concerned. This lady walks by and my foot was out so she patted my foot and covered it up".

"They make you feel you're going to get the best of what ever they have, whatever is there. They can't take the pain away from you but they'll do their best to try and help you."

MY EXPERIENCE DURING DIAGNOSTIC TEST .....

"The staff were all caring. Everyone was wonderful."

The second interview took place in Marion´s living room her ranch house one month after she was discharged. The background is busy with the activities of family life. Her male companion is in his early 70´s and recently had a CVA which now requires him to use a cane walking. She introduced him as the "owner of the house".

AFTER I WAS DISCHARGED .....

"I came home with the tube (foley catheter) and that made me nervous. I was thinking maybe I could stay until that was removed and I was a little bit nervous but .... it made me nervous all the time. I had a few bad days. I´ve forgotten what this is but I made it through."

"I´m a little apprehensive. The doctor told me not to lift anything heavier than 25 pounds, and I can´t go down the cellar steps to do my laundry. I feel like I don´t even want to work on my car. Will and I fix our own cars."

"I´m trying not to call and say can I do this, can I do that. Most people who have surgery that´s the first thing that they talk about. When you think about what your body has been through.... But you still kind of heal from the inside."

MY REFLECTION ON CARING ....

"I didn´t know what to expect in the hospital. I´m extremely grateful for anything that was done for me. I´m really not a nice person. ... the outside personal concerns were away from me. I felt comfortable with them. I´ve got a job to do and here I am nothing I can do .... you know they were there if they could help. I found that wonderful".

"I was so impressed by the hospital. I am concerned about my ability to pay the hospital and the doctor. I did get some help from the financial counselor of the center".

"DR. H. has just been so wonderful. I can't get over the fact that he is able to help other women in spite of the fact that his wife was recently diagnosed with cancer of the uterus".

"But I can't talk to him (Dr. H.). It's not because of him, I can't talk to any doctor. They ask me question I answer them. They explain something, and I'm lost... I don't understand them. In my mind I have questions I want to ask when I get in there. Questions I have I just draw a blank when I see him".

"I don't have a private doctor (primary care). It's hard to have a personal conversation with a doctor. I can't say anything to him".

"We were brought up to so highly respect authority. I had a fear of anyone in authority like a principal of a school or father, mother. I wish I could be more relaxed".

"I'm vindictive, crabby, suspicious. I cry because I want to be the real me. I care when my family fails. Financially I can't do anything but emotionally I care. I try to but rejection is hard and I don't want to be rejected. It's hard to get it across that I really care. If you're in a habit of reaching out and somebody don't hear you. It's kinda hard to know when to say something or not to say something. It's kinda hard not to be fearful".

(What about the nursing staff? Did you feel they created a caring experience and could you speak to them?)

"Oh yeah. They said just ring the bell if you need anything. I never rang the bell. I was comfortable with them. I knew they were there".

"I couldn't believe how nice the housekeeping staff were. I wanted to cry. I felt like I was in heaven with all the pain of the hell outside of you. The knowledge that someone was always right there...you can't take it away from you".

MY REFLECTIONS ON NON-CARING .....

"No not at all... couldn't ask for anything nicer. I get very depressed and my family pays for it. When you are with other people you don't release those parts of you".

CHANGES I'D LIKE TO SEE OCCUR IN THE HOSPITAL NOW THAT I AM HOME .....

"None, I had no expectations, you don't know, but what I got was fine. It made me feel good..... everyone was tremendous".

Story #6 : "I'm Just Waiting for Something to Happen"

Thomas is a 69 year old retired postal employee who up until nine months ago was a healthy person. At that time his doctor found he had a bone marrow disorder that causes a malfunction of the red and white corpuscles.

Two months ago they deceided to place Thomas on twenty-four hour chemotherapy for three weeks period. The doctor ordered a groshong cather to be inserted so the chemotherapy could be administered at home. Unfortunately the patient developed an infection which the doctors believed was caused by the catheter.

An infection during chemotherapy is difficult to manage because the patient does not have sufficient white blood cells to combat the infection. In Thomas's case, one complication led to another. He was admitted to the hospital and given antibotic therapy to control

the infection but shortly developed a severe erematous (rash) over his entire body. This was followed by renal failure due to nephrotoxicity, a secondary complication caused by the aminoglycoside (antibotic) and volume depletion caused by ersematous.

Thomas lives with his second wife in a home north of the hospital. He was referred by his local primary care physician to the University Hospital since the community hospital did not have a hematologist.

His general appearance at the time of the interview is that of an obese male who is extremely flushed and edematous due to the severe ersematous. He appears anxious, impatient and worried about his prognosis. The medical record has a notation from the nurse that he stated:

> I can´t stand it. I just wish I´d die. If I knew all of this was happening, I´d take a gun to my head and shoot myself.

I FIRST CAME TO THE HOSPITAL .....

"Two weeks ago this morning at about five in the morning. I woke up with chills, shaking .... took my temperature and the reading was 103.9 so I called down here and they said to get down here right away. My wife was going to drive me, but in all the excitement I tried to get dressed and I was very weak, in fact I didn´t realized but I passed out a couple of times."

"My wife called the ambulance and it turned out I had an infection and they gave me antibotics. One of them caused a severe reaction, rash all over my body,

and on top of that they have given me fluid because the kidneys started malfunctioning. Between the two of them I have had ....."

"A week ago this morning about 3 o´clock I went to the bathroom and realized that I was going to do well to get back to bed without passing out. I managed to flop on the bed and push the call button. Then about 11:30 that morning I was in the bathroom, they put me in a chair at the sink to wash up, as soon as she (nurse) walked out of the bathroom I knew I was going to go. They picked me up off the floor, no pulse. Laying down my blood pressure was all-right but standing up ..... at one point it reads 120, when I stood up it dropped to 70. So they took me off fluids yesterday, first time I haven´t had an intravenous line hanging from me for two months. So now I´ll wait for this to subside, go home for a while and see what happens there."

A CARING EXPERIENCE IS .....

"Both my wife and I commented on everybody is efficient and very caring."

(Could you describe what makes them so efficient and caring? What behavior do they do that conveys this to you?)

"Their attitude, smile, and the way they take care of you. I´m impressed by the whole system here ... the teaching, the school, and the setup... primary care nursing system. One nurse takes care of all your needs. That way she knows everything is taken care of. It´s not a question of somebody else doing it and not doing it, or not done because of lack of communication."

I´VE NOTICED ..... CHANGES IN CARING OVER THE YEARS.

"Much more aware of what you need. In the old days they didn´t seem to have enough help. It was a little disorganized. It was a long time ago and I don´t remember the details."

(What stands out as being different today?)

"You didn´t have a nurse assigned to you. Sometimes you needed help and waited a long time to get it. You resign yourself and take what happens to you."

"Today there is always something going on, somebody coming in to check on you, the different

departments. The dermatologist, the infectious disease people interested in your rash, might be infectious origin rather than a result of an allergy to antibotics, and the renal department with the kidney problems, beside your regular doctor or hematology people. So its never a dull day."

"The nights are the worst part of it. I can't get to sleep and I am physically tied but can't get comfortable, toss and turn."

I FELT ..... DURING TEACHING ROUNDS.

"Primary doctor comes in with 5-6 residents and interns or what ever and generally they're in the background. They're there primarily for learning and sometimes they'll discuss something. It really doesn't affect you too much. That is part of the system and you go along with it. It adds a little more interest to see more faces everyday and get to know them."

"Generally they talk to you and see how you feel, tell you what's going on. They might discuss other parts between themselves in the room or they may discuss other parts between themselves in the room or they may go out in the hall. They discuss different aspects of the case. I can ask questions that I may have ..... comment on what I think is going on. They want to know what I think is going on. At this point I just go along with what is prescribed."

MY RELATIONSHIP WITH MY DOCTOR IS .....

"Dr. R. (hematologist) is my doctor and she has been my doctor since this started. My doc at home, I had a physical the day before I found out what was going on. He called me at home, said I had a serious problem. I was admitted to North Community Hospital and then they sent me to the University Hospital because they didn't have a hematology clinic. So I came down here the next afternoon. I go in for a blood transfusion at the community hospital in between. I had 16 pints of blood so far, 4-5 units of platelets."

(How would you describe your relationship with your physician?)

"Very good. My wife particularly likes her. She is capable, dedicated and caring. Dr. P. has been head of the team. He and Dr. M. are the three in charge of the

Hematology Department. They come in everyday with a few other residents. The house staff are personable young people."

"Before I started the chemo program I had three options: first, was the heavy dose chemo which they didn't recommend and didn't want any part of; and the second choice was to let things go and do transfusions as necessary and just hope that infection or bleeding wouldn't occur, but it was bound to sooner or later; and the third was the light dose treatment which was three weeks continuously. They hoped to stimulate the bone marrow to function again. There was no guarantee, only a 25-30 % chance of positive results. I said its better than nothing. (Patient took the third option).

(So you believe that it is important for a patient to have choices?)

"For something like this ,yes. For something else... if you need a triple bypass there are not too many options, obviously you are going to do what your doctor wants."

MY RELATIONSHIP WITH MY NURSE(S) IS .....

"My wife and I remarked the nurses and techs are bright, efficient, young woman who know their job so well and know the technical detail."

"The nurse who was assigned to my case when I first came in here to start chemo treatment, that was the second admission,.... I was here for 3 days for the first time. I was her 8 days the second time... and the young nurse at that time was a bright, personable young lady. Very impressed with her attitude. And there has been a young nurse on this floor who was quite personable, laughs."

NURSES ARE CARING WHEN .....

"They transferred me onto the other corridor for heart monitoring. A couple of days ago Sandy came over to see me about 7 P.M., (nurse visits the patient on another floor) she was going off duty. She knew I'd have to come back to this area for chemotherapy since they didn't do that on that floor. So she said she'd clear it with admissions to come back down here that night. I really appreciated it. She was the one who was on duty the night I passed out in the bathroom. She kidded me about getting even with her for giving her a lot of grief. She's a great kidder. It was especially

nice of her to make sure I got this room because I didn't know when it would be available. This room has a better view and when you are in bed all day you really appreciate those little things."

The second interview took place in John's living room. His wife plays an active part in this interview. She is optimistic, warm and concerned about her husband's welfare. The wife was in the kitchen baking a pie at the beginning of the interview and later joins in the conversation. The house is small so she was able to hear the interview while she was in the kitchen.

AFTER I WAS DISCHARGED .....

"When I first came home I was quite weak, but since then have received several pints of blood and feel stronger."

"They filled me with about 40 pounds of fluid (in the hospital) because of the kidney problem. When they stopped giving me the fluids I weighed 200 pounds, now I'm down to 145. When I went into the hospital I weight 169, and when it first started in June I weighed 180. I wasn't eating prior to going to the hospital."

"Now its sitting around and waiting for something to happen ..... which isn't pleasant. Doctor tells me I could go 7 or 8 months or 7 or 8 years. They don't know yet how I'll respond. So you always have that in the back of your mind, what tomorrow is going to bring. She's (pointing to his wife) the one who keeps me going."

"Doctor keeps asking me if I was exposed to chemicals and I said no. I wonder if there is a connection between radon level they recently discovered in the post office and my leukemia, but I was told radon causes lung cancer not leukemia. I still wonder if there is a connection."

MY REFLECTIONS ON CARING .....

Thomas : "Everybody was very efficient and very caring ... and on the first three days I was there I was up and around, and then I was sick. They were so good that I didn't realize I was so sick. I didn't think I was going to make it." (Tearful)

Wife : "I was so anti-doctor, anti-hospital, anti-nurse before he went in there. But the care has been so ..... every nurse down there is so wonderful. Sandy the last nurse was so super dupper. He'd been in there so much and had so many nurse. We didn't run into one who wasn't caring. I couldn't get over it. The whole hospital, the staff going in and out. Everybody is just so wonderful. There wasn't one time and we've been going there since June."

"My mother at 85 had a knee operation she had her hip replaced at North Community Hospital and had to go in there several times. I wasn't happy at all. I just couldn't get over the difference down there."

Thomas : "Dr. P. even brought me in some of his opera tapes for me to listen to."

"Peggy down in the infusion room (ambulatory clinic). You sit around and wait and on one Tuesday they cancelled the appointment. Peggy calls me at home to see how I'm doing. I couldn't believe that she called that Tuesday to see how I was feeling. That's above and beyond."

Wife : "To me the atmosphere has so much to do with it, and when you go in there it's a good atmosphere and to me that's the difference between going to North Community Hospital and going there. But the other day when you (husband) went to North for your transfusion I must say they were nice. I think people who work in oncology are special."

"Everybody down there even though they were rushed and there were so many people, they still don't get excited. They keep their cool. You might have had to wait a little bit, but every where you have to wait. There are a lot of other people there, you just can't ..... And Sandy, the nurse who was there the night they checked his heart, she stayed after work until he got over it. It was little things that make you feel you are special."

Thomas : "When I left the hospital Sandy kissed me goodby like I was her father."

Wife : ""Ya, she´s very warm. She has a limp and a definite limp I never noticed before, but she goes along like a little ..... lightning rod."

MY REFLECTIONS ON NON-CARING .....

Wife : "There´s only one complaint I have. That surgeon who was in charge when he had the catheter put in. He can take a long holiday. John has a very high pain level. He (student) couldn´t get it in and the surgeon who finally took it over pushing and shoving. He lost his cool."

Thomas : "They put the single luman catheter in without any problem. They gave me lidocaine and sedated me. The second time they didn´t give me any sedation so I was probably more tense. The second one was a double luman and the tube was bigger and they couldn´t get it in there. I was holding onto the table. It wasn´t very pleasant. They did give me some lidocaine but it had worn off. He took it out and started to sputter about my anatomy .... there was something wrong with my anatomy. He said ´I never seen a man as dry as this one.´

"Whether he couldn´t find the vein or what it was. So it wasn´t very pleasant the second time. By that time, after losing so much weight, there isn´t much flesh there just skin and bones. For one thing, I had to wear the isolation mask and they draped the sheet over my face. I feel claustrophobic to begin with. Anxious for them to get it over with. I told them if they were going to try it on the other side, put me under."

The surgeon replies, "no way am I going to put you under for something like this, it´s too minor."

Thomas : "I told him, you go through this and see how minor it is. Now the bone marrow biopsy they say is suppose to be painful, but that didn´t bother me."

Wife : "The thing I didn´t like about it, it really turned him off from having that done again."

CHANGES I´D LIKE TO OCCUR IN THE HOSPITAL NOW THAT I AM HOME.

Thomas : "The food. I don´t want to go back."

Story #7 : "I Feel Like a Freak"

Dorothy was brought to the hospital because she developed a cellutitis on the left hand which was caused by a cat bite and an immmunocompromised condition due to chemotherapy. Dorothy had been on chemotherapy for a lymphoma when this injury occurred.

A 65 year old retired high school teacher, Dorothy lives with her husband Jack, a retired school principal. Both of their children are also college graduates and live close by with their own families. She speaks proudly about the accomplishment of her children who are also teachers.

Dorothy is a petite woman who speaks softly and with great thought before sharing her ideas. She is still in a state of shock that she has a lymphoma and is guarded about her prognosis.

I FIRST CAME TO THE HOSPITAL .....

"I have a lymphoma and I have been on chemotherapy .... I feel like a freak... this stray cat came by who was starving, and of course, I had to feed him. He was at war with my younger cat, and while I was feeding him my cat lunged for the stray, and my hand was in the way .....and he bit my hand. My husband told me not to take him in.... I guess he was right".

"So then I called my primary physician in town and he suggested that I come to the hospital. I didn't... Then as the day went by I noticed it was beginning to swell and I was beginning to get anxious about it. The

next morning I saw Dr. P. (Hematologist) early, and he took one look and called in the infectious disease people and they said I had an infection, and here I am."

WHEN I WAS ADMITTED I FELT.....

"Dr. P. seems to be someone who gets thing done. I was surprised, but I shouldn't be, because it must be an act of denial on my part to find out that I was on the oncology unit, and I don't know if the level of care is different here, but it is remarkable. Everyone of them. There was a woman who ... and they referred to her as hon... they were doing things that were psychologically supportive and I could see a little bit of what they were doing".

A CARING EXPERIENCE IS .....

"I would say that they were remarkable and feeling. I can't tell you how many times they said, do you want anything? Can I get you something? That's important when you are laying here hooked up to an IV. Once before I was in the hospital for an operation and I know they are short handed, but at that point I was also hooked up to an IV, and was more helpless than I am now....and two or three times in the night I was absolutely desperate for a nurse to help me go to the bathroom and had a long desperate wait.... nobody came at all. I'm sure that must be due to lack of help. I would say the level of care is more supportive on this floor than it was on the surgical floor."

NURSES ARE CARING WHEN .....

"On the oncology unit the nurses frequently poke their head into the room and ask if things are all-right or if you need assistance. It must be the level of nursing care is greater on this floor than was present on the surgical unit."

MY RELATIONSHIP WITH MY PHYSICIAN(S) IS .....

"Very helpful in that they tell you exactly your situation and possible alternatives and .... these are the choices. Now girlie, don't worry about a thing. Not patronizing. They were honest which I appreciated. I thinks everyone likes to be leveled with honestly".

A NON-CARING EXPERIENCE IS .....

"I had a friend who had an absolutely horrible experience with a physician, a gynocologist, who felt a lump in her stomach. So she went to a surgeon and and he felt it was an inoperable malignancy and sent her home. She went for a second opinion and had an operation and it turned out it was a fibroid tumor, and you can imagine the trauma that she went through being told about making her will. It was absolutely insane. The doctors that I've dealt with.... they are not all born tactful".

DOCTORS ARE CARING WHEN .....

"Dr. P. is very warm. First time I finished chemotherapy he hugged me. I'm not sure that all the doctors go around hugging. And after the first... there he was on the phone calling to let me know he was there... If I was experiencing difficulty he would think of something to do about it".

"I watched him get on the phone when he didn't have blood work and get the information he needed to know. He has a way of getting other people to get the right information.....he gets things done. He is considerate of the other people; he's tactful."

I FELT .... DURING TEACHING ROUNDS.

"I don't mind it at all. I understand that this is the only way that they can learn. Dr. P. is a born teacher. I watched him use leading questions and getting responses from them (students).

(Do you feel like you are apart of the discussion or do you feel outside the process?)

"Not at all. I don't feel like exhibit A. And they almost always, every one of them, make it a point to ... some kind of rapport like they are interested which I think is important... I haven't felt like I was about to be dissected".

"Everyone of them tries to make eye contact with you and establishes some kinda rapport."

MY RELATIONSHIP WITH MY NURSE(S) IS ....

"I can't help wondering of working in the oncology section if they got special training knowing that all

their patients are scared to death, that they understand the patient and are trained to be alert to little things. I can't generalize. I don't have enough evidence".

NURSES ARE CARING WHEN .....

"I've seen quite a little of Andrea she has been wonderful. ..... verbal explanations, and why they are doing it. It wasn't just routine, just a job to them. They understand what you were experiencing...."

"There have been a number of nurses that have been in and out.... but I really think it's a policy to have.... Having the same nurse so you can establish a relationship with I think is what makes a difference. you are comfortable to approach those questions that you feel are frivolous or childish. Anxiety type questions."

MY EXPERIENCES DURING DIAGNOSTIC TESTS WERE ....

"Well.... diagnostic tests to find out what is wrong with me.... And I felt Dr. P. ... so again, warm and supportive".

"CAT SCAN at night was scary.... It's a cold, forbidding, scary place. It's similar to an abandon garage. Very few people around so it was frightening. I don't know what can be done about that."

CHANGES I"D LIKE TO SEE IN THE HOSPITAL TO MAKE IT MORE CARING .....

"In the clinic you have to wait too long for chemotherapy. You come in and get blood work and then you wait and wait for the lab work and the chemotherapy to be mixed. Dr. P. suggested that I come in the day before for lab work. This seem to reduce some of the waiting time.... 8:30 am to 3:30 most days..... that's a long time".

The second interview took place in Dorothy's living room of her home. She begins the interview discussing her image of the University Hospital before she was a patient and what she anticipated would be the level of care.

MY REFLECTIONS ON THE CARING .....

"Well I must say that my opinion of my stay has not changed a great deal... I think... the hospital itself being a gray, huge, politically inspired, hailed in the community as political .... especially coming from a community that has a smaller hospital, that people .... in spite of the fact that it is a tremendously big place..... I was very, very impressed with the way that it had pulled together and worked together. The different departments seem to be genuinely concerned with doing their level best for the patient. I think that it is amazing that they were able to do that.... the size and complexity of the place".

"I expected it to be mass production .....very large with procedures that were set up. I expected it to be far more impersonal. For one thing, I was impressed that everyone who came near me identified themselves and took the trouble to wear some kind of identification, and took the time to establish some kind of personal rapport."

"Everyone who I dealt with made a real effort to let me know what they were doing, and that´s kinda risky because they tell you what´s going to happen to you. Of course two hours later if it hasn´t happen to you and you say what´s going on, but on the other hand it´s really a good thing because the patient is far more involved and informed and if it isn´t happening you can ask what is going on... shouldn´t this be going on".

"I can remember one night they brought me in a supper I wasn´t suppose to have and I questioned it. Well they checked and I was right so they took it out. So it saved me a lot of trouble and them a lot of trouble. So it makes it more of a cooperative venture"

"One of the things that impressed me the most was the relationship with the doctor. He handed me his home phone number which I thought was an astonishing thing. He said, I hope you won´t over use this, but its there if you need me. This establishes a wonderful relationship right there. "

"Calling in the other departments for their expertise is an example of caring."

AFTER I WAS DISCHARGED .....

"My hand is better. There is a scar. The stray cat has now gone to live over on Brown Street. We found a home for it and I waved goodby to it. My husband had a dream in which he would take that cat around the house with a mallet going bang, bang. It was time for the cat to go".

"I responded well to the antibotics because were able to distinguish what kind of bacteria they were working with ... I thought that was good example of expertise, a great strength of the hospital".

CHANGES I"D LIKE TO SEE OCCUR IN THE HOSPITAL NOW THAT I AN HOME.....

"Night staffing. Especially in the areas where they had people who had recent surgery".

"Other than that, I really got more service than I needed. While I had the hand in the cast the nutritionist said ´don´t you need your food cut up´ and I said that would be nice. The next day all my food was cut up...the sandwiches, meat etc. My goodness what care. I thought it was amazing."

"An important element of caring is the continuity of the same nurse because of the relationship is important".

"As for medical care I am unable to identify changes because I lack the knowledge to judge what could be changed".

"As for the students I certainly accepted the fact that they must learn and I thought that was done well. At least what I could see. Dr. P. is an excellent teacher the way he draws the students out. I was impressed"

"It is difficult in clinic because of waiting for blood work for chemotherapy. If anything could be done about that, that would be great".

Story #8 : "This Is My Body"

Sam is a 46 year old male who has been divorced for the past two years. He recently made a career change from being an accountant to a builder. He was admitted to the hospital for multiple trauma sustained from a two story fall while he was building a house. He endured a cervical fracture of the seventh vertebrae (C7), a dislocation of the fifth and sixth thoracic vertebrae (T5, T6), and a fracture of the left radial head. He also had a tear in his aorta.

He was airlifted from the community hospital to the University Hospital because of the complexity of his care and the concern that he may not survive the accident. Sam was awake, alert and oriented to the events which surrounded him from the moment he fell from the roof and landed on his left side on the beach in front of the house. It was a frightening experience and one in which the threat of death rarely left his mind.

His former wife visited him several times while he was in the hospital along with his son and daughter. Sam has been living alone since the divorce and moved into the first floor of a single family home. He rents the second floor to an elderly couple.

Sam is a rather aggressive man who speaks his mind. He frequently refuses to allow the doctors to do anything until he "gets a clear explanation of their plan of action ". The resident´s note on the medical record describes him as being:

> very obstructive and belligerent in patient management, complaining and resisting some therapeutic interventions, ie. nasogastric tube, and foley.

Because of the nature of the injuries, Sam is placed on a stryker frame rather than a hospital bed to immobilize his body and spine and prevent any spinal cord damage. A stryker frame is about half the width of a normal bed. It is on a turn table that allows the nurse the capability of turning or "flipping" the patient from the supine to prone position while still maintaining an immobilization of the spine.

A Pain Control Assist (PCA) is in place to provide Sam the capability of regulating his own pain medication. The PCA is a machine that computes and controls the medication administered by the patient in accordance with the prescribed dosage of intravenous medication ordered by the physician.

"I FIRST CAME TO THE HOSPITAL"....

"Took a ride in the big chopper. I said to myself, this is it, or I´m going to be a quad all my life. I was lucky. "

"The AMP´s (paramedics) started treating me right from the beginning. They started monitoring my vital signs and started an IV right away. From there they took me to General Community Hospital where they began to question the possibility of an aortic tear. So they called University and up, up and away."

WHEN I WAS FIRST ADMITTED I FELT....

"During the first 37-38 hours I received constant service. I didn´t know what to expect. No one took the time to explain to me why I was even brought here. I had a lot of questions".

"I had difficulty getting to sleeping. The nurses took my blood pressure and pulse every four hours. I couldn´t get back to sleep once I was awaken. I had a lot of questions on my mind...."

MY EXPERIENCE DURING DIAGNOSTIC TESTS WERE.....

"This test, that test, I am one who is very ... I guess I want to say meticulous about what happens to me. So when the doctor said send me down for an angiogram, I said, "what´s an angiogram? I made them explain in detail what they were going to do and they did".

"They explained a lot of other tests they were doing; what´s next... and why they were doing it. Because I questioned categorically what they were going to do because I wouldn´t accept...´ your´re going down for a CAT SCAN´. So why the hell am I going to a Cat Scan?"

"I´d ask when are you going to fix this (pointing to his elbow)"? They had a certain methodical movement to what they were doing... which is good. It certainly helps the patient to move through the steps in a proper way".

A NON-CARING EXPERIENCE IS.....

"Two things I´d be critical of: 1) patients have to know what they are doing and, 2) there are many things that are repeated over and over because there really isn´t enough time basicly for combining and disseminating the information. In other words, I hate to tell you how many guys I told I fell two stories or I did this or did that,..... why I did this or that".

"The first 38 hours I was here, and at least every day, I answered the same questions to all different people, from all different departments, who use the same information differently. That´s aggrevating, especially when you´re in agony. All I wanted to do was smash them in the mouth. But fact of the matter remains, they funnel information they want almost in an intimidating manner for what they want done. I had staff come to see me they got tearing at me because of my attitude toward them. That´s too bad. I am not a slab of meat or is anyone else who comes through these doors. We come here to be served as citizens. For the most part third party payors are picking up the tab or the Commonwealth of Massachusetts".

"Now most of the docs and nurses, etc. are working in the finest teaching hospital in the country and they should be appreciative about it and not snotty about it. A little more cooperation between them and the patient may go a long way as far as attitude goes".

DOCTORS ARE NON-CARING WHEN ....

"A real critical note ... I´m going to be lying around here for a few days waiting for my back brace to show up. There has got to be a better way for anticipating this because it´s a very draining and aggrevating situation for the patient lying here for four extra days. I can´t sit up until I get that brace on. I don´t know about other patients, but I can´t eat lying down. Waiting for a back brace...ordered Friday and won´t arrive until Tuesday. Fortyeight hours of stay here or getting out is important to a patient".

A CARING EXPERIENCE IS .....

"The care I got here ...oh I could knit pick about things, but these gals here are superb. I just drop my call button and two seconds later a gal is here picking it up. And they have just made sure that everything is just so. I will comment on one though, and that ´s because we haven´t been in a position to do it. My hair hasn´t been washed. Its kinda tough to have someone who can´t stand up and wash their hair. So we´re still carry a bunch of beach sand in my hair".

COMPARED TO MY EXPERIENCED IN A COMMUNITY HOSPITAL...

"Oh there´s a decided difference.... its size, scope, people, attitude, equipment. It´s the difference between a PT boat and a battleship".

I FELT ...DURING TEACHING ROUNDS.....

"5:30-6 A.M. Did you ever have the urge to kill? Finally fall to sleep and someone yells into your ear,´this gentleman has´. That´s a draw back. It´s hour that bothers me."

"I think they do a pretty good job. You are the object of their discussion"

(Do you feel apart of the conversation ?)

"No. The intent of the rounds is merely to communicate with each other. I don´t see or understand the significant of the rounds. They don´t do anything for me".

MY RELATIONSHIP WITH MY DOCTOR(S) IS.....

"Dr. G. (orthopedic surgeon) I´ve only seen him three times. He´s a nice man, knows his staff. He is an excellent doctor."

"When I met him I nailed him (asked him a question) and he responded. He is the one in fact who said to me, do you know why you are here? Prior to that time no one explained the seriousness of my injuries and why I was airlifted to University Hospital. Dr.G. helped clarify my concerns and fears as well as answered many of my questions. He even answered some questions I was afraid to ask."

(What is your relationship with the house staff?)

"Pretty good people."

DOCTORS ARE CARING WHEN ....

"When I questioned why the need for an angiogram, some of the doctors were annoyed that I dare question their orders, after all they were the doctor. But it was Dr. G. who took the time to explain the rationale for the test and explained their fear that I might have an aortic tear. The angiogram helped them to see the extent of the tear. I still didn´t know why the tear didn´t happen the first hour? So I wouldn´t accept his

explanation until he explained the tear could rupture the aorta and can even occur several days after the initial trauma. If the tear was present, it could have killed me, so they need to know what they were dealing with to plan the proper medical treatments. That´s my kinda guy. Honest. Pulls no punches, direct, tells it like it is."

MY RELATIONSHIP WITH THE NURSE(S) IS.....

"Excellent . There are three of them that really stand out. I drop my call light and in a matter of a second one of them is at my bed".

"Some days I really feel miserable and I´m kinda obnoxious I know. But these girls take it and there always there regardless of my mood. That´s important."

CHANGES I"D LIKE TO SEE OCCUR IN THE HOSPITAL TO MAKE IT MORE CARING.....

"Communication between the physician and the patients. Would like to see the patient play an active part in determining the treatment plan and course of medical care. Would like to be more independent. For example this pain medication machine (PCA) allows me to be independent. If I need pain medication I don´t have to wait for the nurse. I just push this button and zap.... I get medication instantly. Nice, that is what I mean. I like having the freedom to control somethings in my life. I certainly can´t control much on this crazy frame".

The second interview took place on his 84th day of wearing a body brace. He is awaiting his clinic visit to see if the brace can come off. Sam´s whole attitide is different that in the hospital. He is upbeat and positive about his life and his care.

MY REFLECTIONS ON CARING I RECEIVED IN THE HOSPITAL.....

"The day before I was to be discharged , actually it was that night, a male night nurse named John

answered my light about 3 AM when I was experiencing chest pain. The nurse sensed that I was apprehensive and frightened and began to quietly reassure me. He took my blood pressure and a EKG. and told me how to breath. He then came back into the room after studying the EKG and reassured me that with his experience with EKG´s I was fine. That was the first night in my brace and I could get up and walk for the first time. So he got me up and walked to the solarium and we talked for a while. He took the time to make sure I was o-k. There are people like that out there".

"I´m sure there are some people out there who drive the staff crazy. But the inability to do things sometimes makes the patient more demanding. I think you temper it with reason whether it be a nurse, an aide or a doctor. But I think they need to put themselves in the place of the patient to understand what the patient is going through. Unfortunately, I think they can only do that for so long. I guess it goes back to does the doctor have a good bedside manner? "

"I spend 9 days on a stryker frame and it was lousy. There were little things that didn´t get done that I didn´t even know because I was so druged, like brushing my teeth or washing my hair. I guess you have to take each person individually. I don´t even remember what I said during the first interviewed, but as I sitting here in retrospect there were people who took care of me who were supper. They were dynamite. Unfortunate in any profession there are good and there are bad. There are people who care about the people they are taking care of in any profession whether it be medicine, law, accounting or what ever. It doesn´t matter. The ones that care make the difference."

"I was an accountant for 25 years and I still get calls from my former clients, and I tell them I can´t help them but they still see problems. They don´t see someone caring about what happens to them. I cared what happens to them."

"I saw nurses who were doing a job. This is too personal a professional to be just doing a job. You can´t get personal with every patient or get

emotionally involved with every patient because you´d be a basket case in a week, but by the same token you´ve got to care."

"I guess the exposure that I had over the last 3 months I was lucky because the nurse they assigned to my case cared, really cared."

"The personal aide (assigned to care for the patient in his home) I had went over board. She put herself out. She´d come over early on sunday morning when she wasn´t even on duty to get me set up and then rush off to church to ring the bells".

"Now that´s people that care. That´s the type of difference that cares. You can´t see it, but its important. You can´t say its in this hospital and not in that hospital because it´s a personal and individual thing. Attitudes of the personnel are important. You don´t want to feel as if you are imposing on them or asking for something that you are not entitled . You don´t want to feel as though if you push the buzzer they are going to think, oh what a pest. You don´t need that. You need to feel that if I need something I could buzz for it."

"It´s a personal need but I need to know what´s going on with my body, after all, it´s my body. I like to feel as if I have a say, and to be informed prior to medical treatment or diagnostic tests are reaffirmed. Dr. G. has been great. He answers all my questions and keeps me informed and included in his thinking about his plan of care. I started to feel more informed once Dr. G. took over my case."

"I don´t recall much about those first few day of hospitalization.In fact I really don´t remember our interview and what I said. What´s important to me is that the care is personal. I wouldn´t say that everyone was perfect, but I was content. I am a lucky man to be alive and that I can walk. My arm is still limited and I am told that I´ll be in therapy for two year with that arm."

"I would still come here for my care if it happened again."

"MY REFLECTIONS ON NON-CARING ARE."....

"No recollection ...I was always treated as a person. I guess the thing that I want to say again, is what is important is, that the people make you feel that you are important."

Story #9 : "I Wish I Had the Same Doctor and Nurse"

John had been experiencing increasing dyspnea in the past weeks, but had decided to wait to see a doctor until his clinic appointment at the end of the month. . His wife, however, became concerned and called Dr. Z., a gastrologist, who John tries to use as a family doctor. Dr. Z. has taken a personal interest in John since he first started treating him some fifteen years ago.

Dr. Z. agrees to meet John in the clinic after his dialysis treatment. Concerned about his pulmonary status, he arranges to have John admitted to the Pulmonary service as an emergency admission.

In the past six months, John has experienced increased dyspnea and an inability to eat without dyspnea and bilateral pulmonary effusion. He notices that his "breathing is better after dialysis. I go for treatment three times a week and have more energy following it."

This thin 61 year old man looks older than his years. He is not new to the University because of multiple admissions during the past fifteen years. He lost twenty five pounds this past year, bringing his

weight to 105 pounds. His medical record reveals that he has COPD (chronic obstructive pulmonary disease) and a history of pancreatitis, liver abcess, coronary artery disease, kidney failure and urinary tract infections. He has been on dialysis for the past three years.

John is a former alcoholic who first met Dr. Z. fifteen years ago when Dr. Z. was treating his peptic ulcer. Since that time he has had a gastrectomy, vagotomy, distal pancretomy and spleenectomy and lysis of adhesions.

John is a retired truck driver with five children. His youngest daughter is a drug addict and of major concern to John and his wife. Since she was unable to provide care for her five year old son, they assumed the responsibility for bringing up their grandson. The relationship between the grandson and grandfather is very close.

I FIRST CAME TO THE HOSPITAL.....

"For primarily the past twenty years I have been a very impassion person, and I seem to have spend more time in some of these institutions than I´ve spent at home. And its been very discouraging, and I was discouraged when I came in this time. I virtually couldn´t breath and I didn´t realize that fluid was building up so rapidly. I didn´t think it would ....that dialysis would take care of all that . You

can´t relate everything to a doctor that happen to you between the time you see him, and something it gets ahead of you."

"I grew up on a farm and I loved horses. So when the kids were grown up we move to South G. and bought a farm". Two sons lived with us until they were 30. I put an apartment on the third floor for one of my sons but he recently moved out".

I"VE NOTICED .... CHANGES IN CARING OVER THE YEARS.

"It´s good. It´s different than when they started .... you have a lot more interns and residents and students around. But the nursing staff per patient seems to have dropped off quite a bit from what it was the first few years. The response time is slow. Before there seemed as if there was always someone in your room to do something for you. Naturally some patients require more time. After surgery you want the response time to be quick. For the most part I think its good".

(Can you describe what makes the care good?)

"I don´t have a comparison because I haven´t been to many different places. I do recall when I was at General Community Hospital years ago there were many nursing students who had so many hours a day on the floor and there were practical nurses. For a teaching hospital they don´t have that kind of an influx of nurses (student nurses) to do these thing for you like personal touches, such as backrubs. And you´re reluctant to ask more than you require when you see that the girls have got their hands full".

"There is a decrease in personal care. It´s not that serious."

MY RELATIONSHIP WITH MY NURSE(S) IS .....

"Their scheduling here .... if you get the same nurse two days in a row you´re pretty fortunate. You´re apt to have one for a few hours. I don´t know what the thing is but... sometimes they work a 12 hour shift and that´s going to screw up the scheduling".

"But I always thought if the nurse came on at 7 o´clock, five days a week and it was the same one it would be ideal. You get familiar with them and she knows what your requirements are. You´d know her

attitudes also. A better relationship than a strange nurse walking in every morning or several different nurses in the course of a few hours".

COMPARED TO MY EXPERIENCE IN A COMMUNITY HOSPITAL.....

"A teaching hospital is difference... primarily you have a lot of interns. The way they get to learn their experiences is the patient being willing to go through these multiple examinations. Each wants to build their report on your particular problems. Its time consuming and if you´re really feeling lousy its very demanding on your patients. I feel they have to learn some place".

"I try and cooperate with them and I don´t mind too much. Sometimes I have gotten a little cross with them. In a regular hospital there is no students and there´s a limit on the interns and residents. Your primary focus is your doctor. In here you see your doctor everyday, but the resident is the one you see more of".

I FELT .... DURING TEACHING ROUNDS.

"I dont´t mind it. I just wonder if they get anything out of it. There can be 5 or 6 at them with stethoscopes and it doesn´t seem to me that they get anything out of it from what they are doing. Dr. C. would come in with 6 and the chief Resident would describe what has happened . I still don´t understand, maybe its the repetition that students understand. How can they learn when they ´re in and out so quickly?"

(Do you feel like you are a part of the process?)

"Not really, I don´t think the patient is part of that process unless he asks questions... and ah, they know how you are they have your chart. They read that and they know how your night was, etc. They basically are coming in to make rounds and if you don´t ask a question they are not going to offer anything as a rule. It just to bring the students around. They talk to each other and occasionally will ask a question".

WHEN I WAS ADMITTED I FELT....

"I had been having difficulty breathing for some time. My wife called Dr. Z. and he told her to come and see him after my dialysis. He arranged for Dr. C. to see me and they admitted me right away and did a

thoracentesis that night. I was going to wait for my doctor's appointment at the end of the month but my wife was worried so she called Dr. Z."

"While I was in Florida I gave up my oxygen because I was feeling better. But I told my wife I'm not going to do that again. I'll keep the damn thing. I just won't use it, but at least I'll know I'll have it. When its something like that you just can't go out and get and ah..... you have to have a pulmonary doctor get you one, and if you aren't familiar with one, you can't get an appointment with one right away".

"Now I was in the emergency room a little over a week ago and they (emergency room doctors) came in to see how my breathing was. They gave me oxygen for five or six hours and I felt great. But by the time I got home I wasn't worth a damn. But they never called a pulmonary doctor and I asked them to".

"It would seem in the ED they took an xray and they could have detected the amount of fluid I had and their pounding on my chest without ... things like that I don't know".

"What I wanted, I wanted them to get a pulmonary doctor to get me a prescription just so I could have oxygen at home, and I knew if I had that, I could function. I don't go anywhere. But if I had oxygen at home, I knew I'd have it when I had dialysis".

MY RELATIONSHIP WITH MY DOCTOR(S) IS .....

"I think the doctors and the nurses are consciously doing what they can and what your particular case and my case requires. Sometime I wish they, the doctors, would be more informative instead of my having to ask the questions because I don't know how to ask some of the things that I would like to know".

"I've had Dr. S. (nephrologist) quite a long while but he still talks around me that I don't always understand".

DOCTORS ARE CARING WHEN .....

"One of the thing I like about Dr.Z. is because he is so familiar with me and he can better explain to me so I can better understand the things that the real doctor or the renal or pulmonary doctor are doing. Their terminology doesn't ..... ah get through".

"Dr. Z. reads my chart and he knows what´s going on but he able to get it across to me better".

NURSES ARE CARING WHEN.....

"I use to wake up early in the morning, 5 A.M. and was hungry so I couldn´t get back to sleep. The nurse makes me coffee and a snack so I can go back to sleep. I appreciate this and I know she doesn´t have to do this. They are busy with a lot of more important things. But it´s these little things that mean a lot when your laying here and can´t sleep".

MY EXPERIENCE DURING DIAGNOSTIC TESTS WERE....

"In the testing areas there is too much time wasted. It is uncomfortable to be lying on a stretcher. It would be better to wait in your room until they are ready to take you in for the test. Nothing is more uncomfortable than a stretcher or a wheelchair".

"The technicians are caring and informative. It just the waiting".

CHANGES I"D LIKE TO SEE IN THE HOSPITAL TO MAKE IT MORE CARING ......

"Information in a language that I can understands. If doctors would only sit down and have a conversation with you".

"As for nursing care to have the same nurse consistently".

The second interview took place a week after John was discharged from the hospital. He looked stronger and less frail than he did in the hospital. " I feel like I´v gained weight. My appetite is better and I feel stronger". He, however, is still short of breath but this time he has oxygen at home in his bedroom and a portable tank for his living room. He smokes a cigarette about every fifteen minutes during the

interview. He states," I know I shouldn´t smoke but it´s less than I use to smoke".

AFTER I WAS DISCHARGED.....

"It was a very needed trip. Just before I was discharged they took a biopsy for T.B. I´m anxiously awaiting results. The pleural effusion is still a problem to me but it is better".

"I´m eating good. I got to be building a little body weight. Keep the fluid out of the rest of my body, the dialysis helps. But they don´t know why the fluid is building up in my lungs...but partly due to my heart. That is the most debilitating thing, it puts so much pressure on the lungs that even with oxygen you just can´t breath properly, walk, talk and eat. The smoking doesn´t help. I´ve curbed it a lot but I haven´t quite".

"I was a little surprised they let me out, but I felt better after they let the fluid out of my lungs. I go back there three times a week. I don´t see a pulmonary doctor each time. I´ m going back to see Dr. Z next week. It´s a little frustrating your dealing with so many doctors".

"One will ...where the things are so interrelated, one will treat you for each different thing...they all talk. They communicate about the problems but it .. I wish it were a situation where one person was doing everything for you, but it doesn´t work that way"

"While I was up there about the second week I had what I thought was a gas pouch. Boy was that painful. I went through a CAT SCAN and some other test and what had happen was my gallbladder had suddenly enlarged and developed some fluid. Then it started to go away. Some of that stuff had blocked my bile duct. Boy was that something."

MY REFLECTIONS ON CARING .....

"It was very good. I had all the medical attention from the doctors that I feel was necessary. I wish it could have gone faster. And the nursing care for the most part is excellent. They have some good nurses there, other then being spread too thin. I remember one

incident where when I called the nurse for my 10 o´clock medication so I could go to sleep, but she had another patient who required far more attention than I, so it took quite awhile before she could get in. The other patient was quite bad so it took quite sometime. It cut down on the promptness to others. All in all it was very good".

MY REFLECTIONS ON NON-CARING....

"No the doctors were willing to stay and answers my inquiries and there are some things that you get in a teaching hospital that you contend with and rather not... you know with students. Those are the days you feel really crappy and you don´t want to be bothered. But for the most part, the resident and the doctors..... I had good experiences with them. Some of the interns are a little, you know, some what less experienced in doing somethings.... slower or less adapt. There is nothing that is less tolerable".

"I had one time, I guess it was last year when they were going to drain my lungs. I had a resident and an intern. It was about 2 A.M. and it was, I don´t know if it was the first time she had tried it, but she had an awful time. She couldn´t find the area where the fluid is. She was rubbing the bone back there with the needle pretty hard. The Novcaine only carries so far over there. That was a bad experience. Finally the resident took over and that took just a minute. I can tell when they are in there I´ve had it done so many times".

CHANGES I"D LIKE TO SEE OCCUR IN THE HOSPITAL NOW THAT I AM HOME.....

"No. They were attentive to me. The ideal condition would be to have one doctor and one nurse. There is differences in doctors and nurses just like there is differences in people. In the ideal situation..... well, it would be like mother and father almost. I guess it would be a relationship that..... I can´t complain but it would be nice to have same doctor and nurse taking care of you".

Story #10 : "I Can´t Talk to My Doctor"

Peter is a 31 year old auto repair manger. He is married and lives with his wife and three children

ages 1, 3 and 5. He is a meticulous guy who takes pride in doing things well and carefully. He has been riding motorcycles since he was 15 and participates in dirt bike races. He is proud of the fact that in all these years he has never had an accident. He attributes this to the precautions he takes in riding and wearing a helmet and protective pads.

Peter insisted on being transferred from a community hospital´s emergency room to the University Hospital after he sustained a traumatic injury to his left foot following a dirt bike accident. He has three hairline fractures of the metatarsal bones and a cellulitus of his left foot. He is placed on bed rest with antibotic therapy.

I FIRST CAME TO THE HOSPITAL .....

"Got in a freak motor cycle accident on my dirt bike and came here for the care because I was told this is one of the best hospitals to come to. They did a fine job fixing my father. Broke a few bones in my foot but they can´t put a cast on until the cut heals and the swelling goes down. I was released, and it got infected. I was readmitted to clear the infection up and thats where it stands. I´ve been here since Wednesday and I want to get out of here".

"Waiting for the cultures to grow so we can eliminate one of the antibotics. The doctor said I might be going home Sunday but he´s gone to the Cape and I won´t see him until Tuesday."

"I´m sure he won´t call in and say let him out. I told them I´m not staying here until Tuesday. I´m going

home tomorrow whether I walk out the door or whether they let me out."

MY RELATIONSHIP WITH MY DOCTOR(S) IS .....

"Dr. S. is my doctor. He doesn´t say nothing. He comes in here and looks. Asks me questions, he has a simple blunt answer, and doesn´t explain anything to you and he´s gone. He may be the world´s best doctor as far as medical technology is concerned. You can´t expect special care from a doctor that see hundreds of patients every day. Your just not going to get it."

"I know a girl who used to work for me and she broke her wrist and they fixed it at Cass Hospital and they did something to her nerve and she had to be reoperated on and the hand was all messed up. Now I don´t want that to happen to me, that why I went to Dr. S. People highly recommended him to me. He put both my father and brother-in-law back together".

DOCTOR(S) ARE NON-CARING WHEN .....

"I could do (rest in bed) this at home. I miss being at home. Today is my daughter´s birthday and I´m suppose to be at a wedding today of a real good friend of mine. They could care less, really. He tells me one thing,.... maybe Sunday and he´s gone and won´t be back till Tuesday. I Know he´s not going to call and say let him out. He knew he was going away for the weekend so why did he tell me Sunday. It only gets me aggravated and I´m only going to get up and walk out. And that´s what I´m going to do tomorrow."

"A resident comes in the morning and he doesn´t even unwrap the bandage only peeks at it. He said that Dr. S. would call.... calls every day and he would mention to him and he has never gotten back to me about nothing. I asked the nurse and she don´t know nothing".

"He (Dr. S.) tells me I have to get into another sport, that biking is to dangerous and the hospital is full of paraplegics and quadraplegics from motorcycles and this and that. Take up golf or something, he said. I´ve been riding for fifteen years, and I´ve got all my equipment every time I get on the bike, pants that are padded, skin pads, shoulder pads, elbow pads, helmets and kidney belts. I wear every piece of equipment."

(But you don´t have any intention of giving up the sport you like.)

"No I don't, no intention whatsoever. And he said don't come and see me if it happens again."

(How did you feel when he said that?)

"I didn't say anything except to myself. Hey, if he doesn't want the business that's his problem. I do .... repair and not that I like to see people get into accidents but that's my livelihood and without people getting into collisions then I don't have work. I'm sure the doctor sees thousands of patients, that's his own business, not mine."

WHEN I WAS FIRST ADMITTED I FELT .....

"When to the Emergency at Cass Hospital... they told me I needed orthopedic surgery that night, and that scared the hell out of me because I'm thinking that the bones broke in half and they were going to have to put a pin in them to put them together. They didn't explain anything to me, what the procedure was, and I got here and they looked at the x-rays and I didn't need surgery ..... three hair line fractures, and a laceration."

"So they cleaned it up stitched it, and I stayed for two days and they let me go home. I came back on Monday and they put a splint on and they did a shitty job at that. I had to cut the splint off so it wouldn't dig into my foot and that wasn't the doctors fault it was one of his staff".

"Late Tuesday afternoon I was feeling lousy, I was running a fever and Wednesday I felt better in morning but in the afternoon I felt lousy, and it was hurting me more that it did at the accident. So I called the Doctor and he told me to come in so he could look at it, and indeed it was infected so I was admitted. You see the doctors in the morning and he tells me nothing. ..what the culture is doing the biopsey or what they call it and how long it'll take the infection to go away."

"Dr. S. wasn't in the emergency room that evening so he had a doctor under him on call see me. But they did absolutely no work other than clean my foot and put four stitches in the laceration and bandage it up. It wasn't like they did surgery on it or anything. They took xrays and never showed me anything on the x-ray where the bones were cracked. I looked on the x-ray and they looked o-k to me. I couldn't see anything".

MY RELATIONSHIP WITH MY NURSE(S) IS .....

"The nurses in the hospital are super. Anytime you got a problem with medication, you know, they are right there. They do a good job."

"Sometimes there´s a little too much. They come in at night and 1:00 in the morning to take your temperature and blood pressure, that must be a rule of the hospital and you can´t do anything about it".

NURSES ARE CARING WHEN THEY ....

"They constantly come in to and check, whether you called or not. They ask if you need anything to make you comfortable, you know."

"Their attitude is nice, They come in here and I´m in a shitty mood and they don´t snap back at you."

I"VE NOTICED ..... CHANGES IN CARING OVER THE YEARS.

"About ten years ago I had surgery on my ear. They did a super job, not even a scar. They did it all through microsurgery. I´ve not noticed any change in the level of caring. That was just an older hospital that I was in but the caring of nursing is pretty much the same".

A CARING EXPERIENCE IS ......

"The caring part of it comes from the nurses you know. The doctors do just what they have to do you know. Caring comes after the thing is put back together than the caring begins".

(So the doctor then is seen as the technical part of putting you back together and the nurse is seen as the person who symbolically represents the caring part).

"That´s right. The nurses make the doctors."

CHANGES I"D LIKE TO SEE IN THE HOSPITAL TO MAKE IT MORE CARING

"Wouldn´t change anything because care is affected by their personality. I would say they (doctors) need to explain more."

The second interview took place in Peter´s living room. He still has a lot of pain and swelling of his foot and continues to have a lot of questions about his condition.

Peter has been on his bike even with a cast on his foot. This sport is very important to him. He´s upset that he has already missed two races since his accident.

AFTER I WAS DISCHARGED .....

"I got home the day after Labor Day week-end, and I´ve been back (to the clinic) one other time, no twice, because one time I went back was two weeks after I got out, then they put the cast on it. They left the cast on for three weeks, and last Monday they took the cast off."

"He told me to exercise it and stuff. I leave it off at night when I sleep, and it hurts in the morning when I wake up. Like I said, on my ankle is what´s hurting. The whole thing swells up, the whole leg. And at the end of the day its sore because I´ve been working right along at my job".

"They never took an an x-ray of the ankle. I don´t understand why it is so sore. The more I walk on it....I have a feeling that the muscles there have been relaxed and that´s why it is sore. I don´t know".

"I want to know how long it will take. It seem like it´s taking a long time. Its been a harder shot than I anticipated. I can´t walk on it or without the cast".

(Have you discussed your questions and concerns with the doctor?)

"He doesn´t talk much. Unless you point blank ask him a question. He does know his stuff".

(Did you ever call him?)

"No, I can´t talk to my doctor. I ask all my question to his nurse."

MY REFLECTIONS ON CARING .....

"He never called me from the Cape. I figure if I were going I wouldn´t call either. The guy apparently doesn´t get much time off and that weekend he was with his family at the Cape. I wouldn´t even want a telephone where I was staying"

"The doctors and the nurses were good. Even the doctors, they were here every morning, bright and early, before 7:00 they were making rounds. I think the care was excellent".

"If I ever get hurt again this is where I´d go, right back here".

"I´ve never been in a hospital before, but if I was to rate a hospital I´d rate it as excellent because I didn´t find anything there that upset me other than not being allowed to go home. They wanted to make sure the infection was under control and I know if I were at home I wouldn´t stay off of it (foot). Besides that, everything was fine".

"I had a decent roommate. They didn´t stick me with a somebody that was... that´s something to think about. We were both on the same channel and same age."

"Dr. S. is an excellent doctor. I saw what he did for my father. I didn´t know any other doctors, but basically they all work together. If one has a problem they consult with one another. It´s like the same type of industry like mine. If someone in the shop has a problem they come to someone with more experience and stir them in the right direction. They have top of the line docs there. So the other doctors are really lucky to be working with these guys".

CHANGES I´D LIKE TO SEE OCCUR IN THE HOSPITAL NOW THAT I AM HOME

"No, nothing it works. They document everything. There is one thing I didn´t like was when they wake you up to take your BP and temperature. It´s a pretty nice place."

Story #11: "What Will Happen to My Son"

Mary has been divorced twice. She lives with her 14 year old son in a two family home in the city. She has five older children who live in the area. Her oldest daughter, Carol, is very attentive and protective of her mother.

Mary is a 54 year old woman with cancer of the cervix. She had to quit her job in the Glass Factory a year ago after her radical hysterectomy, urostomy, and colostomy. She has been receiving radiation therapy and chemotherapy for the past four months and developed swelling, pain ,redness, and some numbness in her left leg. The swelling in her legs increased post surgery. Her admission diagnosis is left deep vein thrombosis.

Mary is a shy, obese, rather timid woman who has difficulty expressing her feelings. Her daughter Carol is present during the first interview.

WHEN I WAS ADMITTED I FELT ....

"I had to come to the hospital a week and a half ago because I just collapsed and I guess I scared my son, but he didn´t say much. He´s a pretty quiet person. He´s pretty independent".

"I came in for some blood work on Wednesday and my left leg was swollen so I had it checked, and that´s when they found the blood clot on my leg."

A CARING EXPERIENCE IS .....

"I think the nurse show that they care and enjoy what they are doing. There are some who aren´t quite as thoughtful. They do what they have to do. I think the nursing care is pretty good."

NURSES ARE CARING WHEN THEY .....

"They´re here on time with pain medication and if you need anything they´re right in. They ask me ....."

MY RELATIONSHIP WITH MY DOCTOR(S) IS .....

"Most of the doctors are caring. Most of the ones I had seem very caring especially Dr. R., Dr. F and Dr. B."

(What makes them seem so caring?)

"I´ve seen some doctors in other hospital that just don´t seem to care. They just go in the room for a minute or so and then off they go. Dr. R. and them stay and talk. Dr. R explains everything...."

DOCTORS ARE NON-CARING WHEN THEY .....

"....ask you a question they give you .... but no direct answer to the question. I didn´t get a very good education so I don´t understand the big words and everything".

I FELT .... DURING TEACHING ROUNDS.

"I feel apart of their discussion. It doesn´t bother me. Dr. R. is always with them."

CHANGES I´D LIKE TO SEE IN THE HOSPITAL TO MAKE IT MORE CARING.....

"To have a different menu for supper and dinner would help.
I think the room could be brightened up they are rather drab".

The second interview took place in Mary´s home.

She had to be readmitted for a low white blood count

following chemotherapy and was very depressed about her

condition.

AFTER I WAS DISCHARGED .....

"I´ve been in the hospital quite a few times since we last met. I come in every month and sometimes twice a month. It´s rather discouraging.....I don´t know what will happen to my son."

MY REFLECTIONS ON CARING .....

"The nurses have been wonderful. Just a few times you have to wait because they are busy, you know. I had very good treatment by the morning nurse and I am well satisfied. I don´t know about anyone else in the hospital".

"I came to the University Hospital three years ago and I still get the same treatment".

"The physicians are very understanding. I haven´t got any complaints about them. They treat me like I´m somebody. I think of Dr. R. just like he was my brother to me the way he treats me. He is a wonderful doctor. So my daughter is satisfied".

"He (Dr. R.) explains everything to you, you know, he explains them to her (daughter) which she likes. She is with me all the time. If it wasn´t for her I don´t know what I´d have done".

CHANGES I´D LIKE TO SEE OCCUR IN THE HOSPITAL NOW THAT I AM HOME

"I don´t know much about caring, but it needs more help, that´s for sure. Especially the ones that clean the rooms. They were awful slow.... three or four hours before... and that shouldn´t be. As far as the nurses here I don´t think you need any more caring nurses than you have now. The help is always cleaning up... they shouldn´t make you wait so long".

"They say come at 8:00 .... about eight hours in the admitting area. And I think that´s undeserving. You are waiting while they are cleaning up there".

(When I use the word caring does that create an image of a nurse?)

"Well, yeah... the physicians too. They do care... Most of them are very caring. I haven´t got any complains about anything else.

Story #12 : "I´m a Professional Too"

Nancy is a 26 year old white female who was recently diagnosed as having cervical cancer. She is an engineer and manager in a large computer company in New England. Her home office is in another state but her parents live within the University Hospital region.

She is engaged to a psychologist who is completing his PhD. Nancy has her own apartment and has been an independent woman since she graduated from college five years ago.

Nancy was admitted for a radical pelvic node resection, radical hysterectomy, bilateral pelvic lymphodectomy, and a bilateral oopherectomy. This young woman will never bear children. Her prognosis is poor.

She is a bright, articulate, well educated woman of the 90´s who is still in a state of shock that this tragic diagnosis has hit her. She tries very hard throughout the interviews to be brave, objective, and optimistic about her prognosis.

WHEN I FIRST CAME TO THE HOSPITAL.....

"I´ve only been in a hospital 2 times. After the pap smear came back positive I was scheduled for a colposcopy and a biopsy. I started hemorrhaging after which was really frightening, and they had to give me

several pints of blood. This time I came in to remove all the cancer cells."

A CARING EXPERIENCE IS .....

"It´s down to the individual person who takes care of you. Each nurse is different some are more technical, some are more personable. Some are better at doing it than other".

"Overall some hospital are better than others. I definitely think this hospital has better nursing care than the last hospital I was in, both technically and the quality of the nursing staff.

COMPARED TO MY EXPERIENCE IN A COMMUNITY HOSPITAL....

"The other place wasn´t organized. The nurses didn´t know what was going on with the case unless they read through the file or they were there when the doctors are there. But for the most part they don´t even know what you have had done, what operation you had. They just know what care is for that immediate time. In here, they are at least a little more aware of what you have had done. That also due to the fact that everyone on this floor is in for the same type of problem, cancer- gynocological cancer. More or less we´re all here with the same type of symptoms and discomfort, whereas in the other hospital they didn´t know what was wrong with me so and they really weren´t doing anything for me . I was there basically for observations and to stop hemorrhaging so they couldn´t answers any of my questions. They really didn´t know".

MY RELATIONSHIP WITH MY DOCTOR(S) IS ......

"I really don´t know him (Gynocologist) very well. I just found him for this operation. But he´s very nice. He has a different bedside manner. He is very quick. Comes right to the point. He tries to be personable. He is just not a personable person but he really tries. You can tell he´s really tries... he really does, and I give him a lot of credit for it".

MY RELATIONSHIP WITH MY NURSE(S) IS ......

"The nurse is the ...is the one who really takes care of you. It´s important that she know the total picture".

"Here everyone knows your name and that´s great. They all call you by your first name. Its nice that

they remember your name. A few times that I called down one of the nurses I know answer (by the intercom) and called me by my name, and that was great. Other hospitals I´ve been in nurses couldn´t speak English".

"There is one nurse who I like a lot, Kathy. She comes down to my room and talks to me even when she is assigned to take care of another patient. She´ll sit and just talk about her life and what´s going on. We compare wedding plans".

(When I ask you to describe caring does that create an image of a nurse rather than the doctor?)

"Yes .. physician is a much more technical job in my eyes. They come in do their surgery, and they just monitor your condition they´re not really caring in the sense that they´re not with you when you are throwing up or when you´re in pain or anything like that. They come in and say,....´oh you threw up´... or ´you´re having some discomfort´. Then they march out and say oh ya give her some of this or that and then they leave. They don´t give it. Oh their caring but its a different type of caring.

NURSES ARE CARING WHEN .....

"The nurses need to be more honest with you instead of... ....if they don´t really know what is going on. But they don´t like to say that they don´t know what is going on so they make something... they don´t really make something up, but they tell you the routine things which really doesn´t help."

"So honesty is very important. If you need some pain medication and they take off and never get back to you for a few hours and then they say, oh I couldn´t get in touch with your doctor. If they told you that up front then you would have been conditioned ... the thing is they don´t tell you and you don´t know what you are dealing with...so the time in hospitals is very long because you are doing nothing. The nurse are running around doing a million thinks. So your time and their time is definitely different".

(Is the hospital boring because you are sitting around waiting?)

"No I had a lot of pain. In my previous hospitalization it was boring because I was laying horizontal most of the time. That was frustrating".

(The control of pain then during this hospitalization is important.)

"Oh yes, especially on this floor. Very important because you are in so much pain. When you're in that much pain your body sleeps a lot more. Your body can only take so much pain and then its got to shut off".

"And in the last hospital some of the nurse wouldn't acknowledge my boy friend. They wouldn't let him in and they would throw him out exactly when visiting hours were over, and stupid things... You know real control things. What difference does it make if you're in a room by yourself. You know, he could be in there all day, who cares as long as the patient care was not compromised. That's what I didn't like about the last hospital. But in this hospital, they are really neat. They don't care as long as it doesn't interfere with your care".

DOCTORS ARE CARING WHEN .....

"I think its important that when the doctors come into the room and the family is there, that they acknowledge their presence and speak to them because doctors can be very condescending. In my last hospital the doctor would only speak to me. She wouldn't speak to anyone in my family because I was 26 and a consenting adult and she use to make my family leave. It was kinda weird.... and a power thing."

"When my family is here Dr. R. acknowledges their presence and answers their questions. I like that. It's important that my family be apart of this with me."

DOCTORS ARE NON-CARING WHEN ....

"I really don't want to continue my care with my gynocologist back home. I feel my condition is more complex and requires a specialist who understands gyn oncology."

"I don't think she was very emphathetic to my condition. I was scared about another biopsy since I hemorrhaged the first time. And she was like ..'why are you being such a baby it's not going to hurt much'. I think she could have been more sympathetic to what I was feeling. It was excruciating pain and I don't think I have a low threshold for pain. Maybe it was the Cervix's abnormal cells or the cancer was in such a position . It was excruciating pain, and not to mention

the psychological condition that goes along with it. I was petrified from what happened before".

"One day she threw me out because I wore a tampon and she couldn't do a paps smear, and that I didn't know when I had my last period. She was just so condescending before they realized the severity to my whole case. And then when they did, they became more sympathetic".

(You felt like they put you down).

"Yea, like I was some idiot that didn't know what was going on. I'm a professional too, so I don't cow because they have a M.D. you know. Big deal.

"I'm a manager of a staff of 10 people. Yea ..so I'm the youngest in my department, so everyone who works for me is older. So I don't need this crap from other professionals. I'm a professional. I'm intelligent so don't put me down".

"We just got off on the wrong foot. But how did I know you are not suppose to use a tampon before you have a pap smear, I was more worried I was bleeding".

I FELT .... DURING TEACHING ROUNDS.

"Very interesting. In the other hospital I was dreaming I was dying and I woke up and there was a group of people all around me and talking about me but not to me.... and all the intern were my own age. It was really weird. Here its more professional. They talk about you outside the room and they come in look at you and talk to you. It's much, much better hospital. At the other place they ask me the same questions over and over over again. I didn't get that here".

MY EXPERIENCE DURING DIAGNOSTIC TESTS WERE.....

"Well all the tests were done before I was admitted to the hospital. When I had the Cone Biopsy, I wanted a - second opinion but I was told there was no other opinion, the cells were so clear".

"I threw up during the bladder xray. Staff were helpful."

(Was there anything else which the staff could have done during these test to be more caring?)

"No.... No changes- handle it well. They don't know your diagnosis. That surprised me. They only know the test you are going to have."

CHANGES I'D LIKE TO SEE IN THE HOSPITAL TO MAKE IT MORE CARING....

"One day all the nurse went to a meeting and nobody was there to answer my light. Someone should be available at all time to answer lights and not keep you waiting for such a long time."

(Were the physicians available to you?)

"The doctors...no, they're available. You see them all everyday. They come back and check during the day if something is wrong".

(Did you experience any incident where you felt it was non-caring ?)

"No. I was impressed with the housekeeping staff who clean my room . They were thoughtful, and intelligent. The staff that come and pick up the trays, too. There is no Black or Spanish, (referring to the housekeeping and dietary staff), ...not that that matters. They like what they are doing, and it's easy to speak to them".

The second interview occurred in her mother's home two weeks after Nancy was discharged from the hospital. The interview takes place upstairs in Nancy's bedroom.

AFTER I WAS DISCHARGED .....

"I came home to my mother's house after I was discharged and will be here for another two weeks .... then I'll go home to my place. I miss being home and seeing all my friends. I'm looking forward to going back to work."

MY REFLECTIONS ON NON-CARING ....

"Since I last saw you I had a very upsetting experience with my primary nurse so that I requested the head nurse to change the nurse because she was so lazy. I'd ask her to do something and she would either

not respond or take her time getting things done. Her attitude about her work was just unacceptable. She was such a poor nurse. She was so not dependable and didn´t care how this attitude affected my care. I needed to have someone I could depend on. Who would be there when I needed help. She did as little as she could".

"The only bad experience I had was when the tubes (abdominal drains) were removed. That was awful. I asked him (Dr. R.) if it would hurt, I wanted to know so I could prepare myself. He told me it wouldn´t, but I´d feel this funny sensation as they were being pulled out. I wish he had been honest. I was in a state of shock for two days after. The pain was so bad I just couldn´t stop shaking for days. He never gave me or offered me any medication for the pain".

(Is it difficult for a patient to bond with a physician or a nurse ?)

"Yes. You have so many different people caring for you. I remember one nurse who I felt close to. She used to come into my room to talk to me and see how I was doing. She is going to get married soon. She used to go out of her way to see how I was doing and was genuinely concerned about my welfare . She somehow always found the time to talk to me inspite of her heavy workload".

"Now Dr. R. is a conscientious physician who is rather awkward in expressing his feelings and concerns. But he really tries hard to be gentle and caring. He seems to understand that a doctor needs to establish a rapport with the patient, but lacks the skill and comfort in expressing his feelings openly. He has became more relaxed with our relationship as time has gone on."

"He is always here. He lives in the hospital. He rounds in the morning and comes back in the evening. Most physicians would only see you once a day. He told me if I needed him or had a question I could call him up to 11P.M. He´s in the hospital until that time. I don´t know when he goes home to his family. He´s always there".

"He is also very competent, practically everyone on the floor (GYN unit) are Dr. R.´s patient. He makes me feel comfortable in asking questions about my condition or telling me what he is going to do. But I don´t always understand what he is saying. So I wait for the resident to comes in and asks him to explain what Dr. R. said".

CHANGES I'D LIKE TO SEE OCCUR IN THE HOSPITAL NOW THAT I AM HOME .....

"As I look back on the experience the only thing that would have been better for me would have been to have the nurse wash me the first few days after surgery. I couldn't shower (tubes and drains were in place) and I was too weak to really wash myself. The nurse came in and set me up to wash myself but I was too weak".

"I really liked the woman who cleaned my room and talked to me each day. She wasn't running around like the nurses and doctors. It helped to pass the time and gave me someone to talk to. Everyone else I talked to, talked about my condition. She just talked to me".

Story #13 : "I Really Wasn't Ready to Go Home"

Marie is a 60 year old white female who lives with her husband and adult daughter. They had recently converted the second floor of their colonial home into a second floor apartment for their daughter. Her husband Bill has severe coronary artery disease and had open heart surgery a year ago. He was a patient at the hospital the same time Marie was rushed to the emergency room with a sigmoid abcess caused by diverticulitis. The doctor and family kept the seriousness of Marie's condition away from her husband until her conditiopn stabilized and he was out of the Coronary Care Unit.

Marie has four adult daughters who all live nearby. They appear to be a close knit family and concerned about the welfare of their parents. Marie is

the center of the family life and uses humor and a assertiveness to convey her feeling and wishes.

At the time of this interview, it is Marie´s third hospitalization. She had a sigmoid colectomy, partial cysectomy, left salphine oophrectomy and an ileostomy just three months prior to this interview. The admitting diagnosis is "rule out bowel obstruction".

I FIRST CAME TO THE HOSPITAL....

"Well I had an ileostomy back in June when my problem first began and they sent me home with this bag. Bill was in the hospital at the time, so I went home with only my daughter to take care of me. I couldn´t get the bag to fit right. So naturally your flesh becomes a ball of meat, so I ran into one problem or another and you know how the insurances are. So they sent me home for a few days and then I came back in and they finished what they had to".

"They brought in this wonderful VNA nurse whose name is Joan Z. You know when you work for VNA or outside of the hospital, medical supplies are not as easy to come by. So you improvise and that is what she did. She showed me how to use it. In the beginning I changed the bag 5-6 times a day and I ended up with once a day, which was terrific for me. I was lucky I came in for a reversal"(referring to closure of the ileostomy).

A CARING EXPERIENCE IS .....

"Bill was in the hospital for a month and I was on the 3rd floor. Everyone knew what was going on with Bill and never told me. When I was better they took me up in a wheelchair to see him. Dr. P´s (Bill´s doctor) nurse came in and sat with me and explained about his condition. When we left they set it up. The second time they arranged for us to go home together. His problem now is, that I´m here and he´s there (home)".

MY RELATIONSHIP WITH MY DOCTOR IS .....

"The the three times I came in I came in on the 4th floor, (turns to her husband and asks) or was that 3 East? I had the most tremendous people working on me. I must say I feel terrific that I have Dr. F. I think that he has the funniest name, so I call him Dr.F. He is a nice, gentle, reserve, quiet person. He is a gentleman in my eyes. I yell at him... I tell I don´t like what´s he´s doing. I tell him I should be at home. Hey, ya gotta tell him.... a guys a guy.... he´d get out of hand".

"He´s (Dr.F.) so dedicated, he´s here night and day I wouldn´t want to be married to him he´s always here. He wouldn´t even be able to go home and sweep my floors. Really, he might be running around with a tittle and money, but that´s all this poor girl got. She´s got to be a saint. I would see him when I was down on the 3rd floor were his office is at 6 A.M. and then later at 7 P.M.. I would see him 2-3 times a day. He never said too much, but hey that gave me that little bit of encouragement that I needed".

"He had this resident with him Paul, the guy was tremendous. He was quite, gentle. He acted a lot like Dr.F. and I think that is why he got along so well with him. And he also would show up twice a day and not that anyone of them talked, but that they were ... it made you feel that they cared that much".

"I had some extreme headaches while I´m here and they (neurologists) keep coming back. When they same team work, they mean team work".

MY RELATIONSHIP WITH MY NURSE(S) .....

"The girls I had as nurses were tremendous. Very compassionate, easy going, were always there for me. I knew nothing... I knew nothing, nothing about the hospital, just what I saw with him, (pointing to husband) no major things. The underneath part is what I´m trying to tell you, you know what I mean? You know about getting a sterile bandage, ringing a buzzer and waiting for a nurse to come. I knew he was being taken care of but I hadn´t had that experience. They were really good to me".

NURSES ARE CARING WHEN.....

"There were a couple of girls that were .. I still say thank god and a prayer for them. Sounds crazy but

they treated me well. One was a little LPN and I don't even know if she was a LPN. She was going to Quinsigmond to become, I don't know... an RN. She was the most gentle person I ever came across and she worked 11-7. She would come in that first week, you know when you are really sick and feel like you are dying, and for no reason she'd come in the room and rub you back or your legs and say 'can I do something for you?' These things mean so much".

"I also met this other person, her name is Mary. She is a colored woman down on that 4th floor and she is an LPN and she is the most energetic person I've ever met in my life. Nice, congenial... would rub your back for no reason. I can't say enough about the girls on this floor, I don't care what capacity they were".

"They would teach you some little thing like how to shut off the alarm on the Imed. It may simple like a simple thing to you but when you are lying here and that beeper keeps going off...it means a lot. To know that you can go for a walk yourself or go down the hall and get yourself a drink. These things are important because I hadn't experienced these".

"The other thing I like, they never come in and hand you a pill and tell you to just take it. They're explaining it ...especially if you are smart enough to ask them. And they'll explain the whole thing to you".

DOCTORS ARE CARING WHEN .....

"I can remember one day they were down in the OR all day long and you could see how drained they were and they came in to ask how you are feeling? I laughed and told them to go home and take a shower and take care of themselves. They looked like they were ready to pass out. Those little things mean ....probably they don't even realize what they are doing but to a person who is sick or who doesn't know anything about a hospital its very important". So all my stays were great".

"After I went home I was with pain constantly. So sunday morning my daughter at 8 A.M., 9 A.M. picked up the phone and called the hospital and asks for Dr. F. And do you know who answered his own phone, Dr. F. And my daughter say, 'what are you doing answering your own phone?' and they laughed. He gave her his own phone number and told her if any more problems occur to call him at home, but he wanted to wait until the VNA nurse

got there to see if it was what the daughter was doing..... But they couldn´t do anything".

"Anyway, they called him back and he was still here, and he said to her.... and these are the things that are very important, ´I don´t want anyone but a surgical resident touching her. You make sure you tell them down there (ED)´. If you´ve been into an ED you know what he mean and I´ve been there plenty of times with him (pointing to the husband)".

"Yesterday I was miserable and depressed. Dr.F. came out of the OR after being in the OR all day and I said to him, hey, I have to know what´s going on and I have to know what´s wrong with me. And he stood there, and the poor guy must have been dying, and he explained what he was going to do. At least I knew what he was thinking. He couldn´t explain what had happened because he didn´t even know but I felt better".

AFTER I WAS DISCHARGED .....

"Sent home after the first surgery, you know how you have to do that before..... before and the insurance sent me home and I really wasn´t well enough. And they taught my daughters how to change my ostomy bag. He (husband) was still in the hospital at the time. It was the most miserable weekend and the bag kept falling off and running constantly (draining stool)."

"The second time I went home Bill became my nurse. You know the insurance will only give you the VNA nurse for a few days. The bag wouldn´t even last a whole day so Bill changed it for me. He was there to help me during the night and helped me."

"Bill even comes to the doctor appointment with me so he know what´s going on. This way we can talk about my conditon. Its nice having someone you can discuss your care with and your concerns. This is important. You know when you are younger you are running around and these things are not important to you but as you get older it is important that you are able to support each other".

"The third time I went home I really wasn´t feeling good, but went. You gotta go, you gotta go. But when I got home I belched for 5 continuous hours and no matter what I did I couldn´t feel good. Eventually the blockage was there and on tuesday

morning the VNA nurse come in and called Dr. F. He told her to get me into emergency room. And here I am."

WHEN I WAS ADMITTED I FELT ....

"I was admitted and who was there but my two friends. Two young men, one just started his residency when I came in the first time. He had three men on his team. The first was a 4 year student, I mean resident, oh my god I know there is a big difference. How could I make such a mistake. (laughs) The two young men, one of the kids had just became a resident when I first came in. He has a three year resident with him, his name is Ben. Nice, nice kid who is going to get some where. He is very conscious, very quiet, and very nice. They were standing there in the ED waiting for me to come in so that no one else would touch me. Now, who else would get this royal treatment. I was sick and dying but that was more important because I didn't want to come back but I knew somebody cared. So that was my second experience coming in and it was like old home week. It was relaxed atmosphere and they were very nice to me."

"So I came back on the 25th and he operated on me. Dr.F. and Paul (resident) were still on my case. Dr.F. asks me if I'd mind coming in 5 days earlier so that the resident (Paul) could continue on the case. After the 30th the resident would be changing services. Hey what did I care, they treated me like a queen".

"They know I love the 4th floor but the day I was in the ER, it was like a zoo, but anyway... even those kids in the ER they were so gentle, so good, they would make up stupid little jokes to break up the tension and it was very nice".

"Today I had to go down to ER for some xrays and a male RN, John, came over to see me. A resident also came over and said hello. Another resident came down to see me and said I was his patient and the ER resident let him take over".

"This time I was admitted to the 7th floor. They were going to send me to the 4th floor and I said, no I am content here. The nurse who is caring for me here is nice, she is so energetic".

"Besides I have such a nice roommate. So I'm content and lucky to be here. This is a better room. It would have a better view if the windows were clean. But I like my room and roommate... and the nurses are good".

A NON-CARING EXPERIENCE IS .....

"It wasn´t the perfect set up. Not everyone was here because they care. You could tell they were here for the benifits or the money. But I wasn´t here for the service. I ´m here because I´m sick".

"There was one incident when the surgery went longer than they had told Bill it would. It took 3 hours instead of 2. He was concerned that something must have gone wrong. To add to the confusion my room was changed to the 4th floor at that time since the hospital moved all surgical patients from the 3rd floor to the 4th. But no one thought to tell me or Bill. The poor guy was waiting and worrying and I was on another floor".

I´VE NOTICED ... CHANGES IN CARING OVER THE YEARS

"The insurance doesn´t cover you like it used to. I really wasn´t ready to go home. It´s a dramatic feeling to go home and have to come in. The bag was not ready to go home, and we are not medical people. You can´t control your (insurance) benefits, and you don´t want your kids to see you. My daughter was taught but it is hard to learn and its your daughter. He (pointing to her husband) was in the hospital for a month and it was put on them".

"The other major difference is the technology and ....it is more relaxed. I don´t think its my age, I doubt that. The tone of hospital is different today. There is more communication to patients and its less formal."

COMPARED TO MY EXPERIENCE IN COMMUNITY HOSPITALS....

"In the past 4 years I´ve been in and out of General Community Hospital for D&C"s. When it came to a major problem they can´t compare with this hospital. I knew this hospital from Bill. Now I wouldn´t transfer after I´ve seen these two hospital."

NURSES ARE NON-CARING WHEN THEY .....

"Attitudes.... oh I´ll be back, or that´s o-k or that´s only normal. You don´t want to hear that. You can tell right away. They were either the very, very young girls or the older ladies who was ready to retire and didn´t care. A person who has been doing this a few

years or in their late 30th, they are very conscientious. They´re great... they are happy".

I FELT .... DURING TEACHING ROUNDS

" If one doesn´t ask the question the other does. Its a real team effect".

(Do you feel like you are a part of the discussion or separate?)

"I feel like I´m part of the team. I ask questions and they ask me questions. Its a real team."

MY EXPERIENCES DURING DIAGNOSTIC TESTS WERE.....

"I didn´t have any problems. Everyone was great. They explained everything to me."

CHANGES I´D LIKE TO SEE IN THE HOSPITAL TO MAKE IT MORE CARING....

"Nothing... even in admitting they were congenial. It´s a team. The physicians were great and the residents were great. That stay was a good stay".

The second interview took place in the kitchen. Rose has been readmitted in between the first two interviews. She appeared to be uncomfortable during this interview as if she didn´t feel good and was weak. A slight perspiration was noted on her brow. She states "its from doing light house work".

AFTER I WAS DISCHARGED .....

"I started bleeding again and I´m going to another GYN. Last time I was in, was September for 8 days because it was obstructed."

MY REFLECTIONS ON NON- CARING .....

"I do have a complaint. The last time I was in there was one night that I´ll never forget. They were short of nurses and asked this nurse to work a double shift. So she is just doing it. She wasn´t the type of nurse I started with but what do I care, I was able to take care of myself. About 10 PM she comes in and tells me I´m going to get a new roommate. So what do I know about hospital procedure, so I say o-k. And 10:30 they roll this paraplegic and this lady wasn´t sick. There is a different between being sick and obnoxious. And the lady certainly wasn´t sick, she knew everything in the world about her condition. If you could have heard the language she was using and the way she talked. She had a big clock in front of her and the minute she didn´t get her medication on the exact time, she was yelling and screaming and I mean screaming".

"And this nurse came in and said: hey, look I´m not your servant".

"She was screaming and screaming, so it would go right through you. So I said to the nurse, there are rooms down the hall, why don´t you put her down the other end of the hall or in a room by herself?"

"She said, well this room is closer and we didn´t want to push her down the hall this time of the night".

"But this woman went on and on and on. I had the first part of the test (GI xray)and I knew the worst was yet to come (Barium Enema). So she says I´ll give you something to sleep, but I knew I couldn´t because I was going for a GI series in the A.M."

"So I ask her, didn´t you read the record? And she said, I didn´t have time to."

"And I said, you haven´t? What do you mean you haven´t? You came on at 7 PM when you changed shifts".

"She walked out the door. I don´t know who she is and I hope I never know who she is".

"I finally fell asleep and about 2 A.M. I woke up and they bring in all these machines for her(referring to the roommate). I feel awful, like the way I did when I first came into the hospital. I´m gasping for breath, so I ring for the nurse and tell her I can´t breath and

I need oxygen. She turns the light on, walks out the door and that was the end of the nurse".

"About 15 minutes later I ring again and say, what is the matter with you, I told you I needed ... I was gasping and she said, 'I took care of it'".

"I said, you did what?"

"She said the woman next store had a bowel movement and I sprayed the room. Between the pump and the aronomia that's what got into the room. Do you want me to spray the room with lysol?"

"I can't believe it. I'm telling you if I knew who this person was I'd fire her on the spot. The lady who was in the room was worst".

"She (nurse) tells me 'I didn't know I was going to get this person and have to work so hard. If I knew, I wouldn't work'".

"I said, listen, because you got the job and are getting paid doesn't mean I've got to suffer. So she said she'd clean the woman in a while".

"Now the lady starts to yell and scream all over again and by this time I'm really going out of my head. That was at 2 A.M. and I must have slept for 2 hours".

"It probably shouldn't bothered me but to tell you the truth, it still is bothering me. I was actually shaking and I don't ever remember being like that".

"This nurse is upsetting me, and she tells me she is going to give me something to sleep. I told her, I told you before I can't have anything after midnight, and if you think you are going to spoil it for me you are crazy".

"People are going to treat you the way they treat you. This girl was driving me crazy and the other patient was driving her craxy. This girl thought she was going to have a nice easy job and that was what she was looking for. Well, tough for her. We all work and no one is going to pay you for nothing".

"Finally about 4 or 5 A.M. I got up. I thought my insides were going to explode. I got up and sat in the chair next to the window. Thank god I was near the window and able to occupy my mind. I sat there and finally I said to her.... she came in constantly, she

did wait on her.... I don´t know know who was going to kill this lady first. But she´d come in, and put this bright light on, and leave this god dam bright light on.....I know its easy to forget, but if you were going by, wouldn´t you shut the light off?"

"Finally I said, I want to see your boss, your superior and she said,´ why?´ Why? If you don´t get one I will".

"So the supervisor comes in, and of course she doesn´t know what is going on".

"The supervisor said; well, we were short handed and she volunteered."

"That´s her tough luck."

"She came back and said,´ we´ll bring you down the hall´".

"I said no. I´m not moving. You take that lady and move her down the hall".

"She said: ´well, that will wake up everyone´".

"And I said, I don´t care. She kept me up all night long. I want her out of here or I´m really going to cause a riot".

"Well it took her from 5 to 8 A.M. to move her out of the room. Now I´m so worked up, my system is tight up in knots. Now I have to go down stairs, and they don´t know why I can´t stay still. Am I going to say anything to them? No. Finally I come up stairs and I tell you I have never in my life experienced a day like that. My insides... when people say they are nervous and that their nerves are shaking them, I never understood it. You don´t understand until you experience it and I hope to god I never have to go through it again. Because even when I talk about it, or think about it, it still makes me nervous. I can´t believe it. It took me from monday night till tuesday night and all that meducation to calm my nerves down. And I would pace. I couldn´t sit, I couldn´t sleep, I couldn´t control myself. Nobody should be put through that experience."

"They finally moved her. They put her in a room with a lady that in a semicoma. Why didn´t they do that in the beginning? Because she didn´t want to push her

down the hall? I honestly don´t know who she is, but god forgive her because it was the the worst

experience...for that kinda a reason? For no reason. Sounds crazy, huh?"

"Think about it. With the insurance company you are still going home. If your not a professional you don´t know".

"The rest of the time I never saw her. I pray for the paraplegic´s husband".

MY REFLECTIONS ON CARING ....

"I love Dr. F. He is so compassionate. I did start bleeding again and I am having a hard time with it and accepting it."

"He has the nicest girl working for him and as busy as she is, you would never know, and she answers all your questions. So she arranges for a telephone conference between me and Dr. F. so I can speak directly to him and answer my questions. So that is why I think he is so great in my eyes. Who do you know that will speak to you on the phone and answer all your questions?"

"He´s made a few mistakes himself, hey don´t we all. But he is compassionate and takes the time to talk, that is if he knows he´s got to talk."

"I have the nicest GYN at General Health Center. I don´t want to leave her but I´m being ...what do you call...greedy I guess. But I don´t want to run around between General Health Center and University Hospital, and my medical records are here. I´d like to stay there, so Dr. F. got me a new gyn. But I´ll let you know what I think of him."

"My husband is still having angina with slightest exertion. So he´s enrolled in the cardiac rehab program. John (a male nurse) watches over him like a hawk. In fact, I don´t know who is the father. (laughs). Bill can hardly wait to go. Insurance company pays for the first 12 weeks."

"For years he has had alot of medical problems. I think that has brought us together. He is so easy to get along with and sometimes too easy. No matter what I ask it´s o-k".

"I've got to go back to work. I love it. I should go do something. He is depressed. He is not eligible for Social Service. We are waiting to see if he is eligible for disability. He's (doctor) got a few more weeks to decide."

CHANGES I'D LIKE TO SEE OCCUR IN THE HOSPITAL NOW THAT I AM HOME.....

"I have only one ...fire that nurse. Oh, I guess it's not totally her fault. There isn't a person who doesn't, who didn't care about you except this one nurse. But you can't just blame this nurse, three quarters of it was that patient. Her husband must be a saint. But the nurse can't be efficient if she hadn't read my record by three quarters of the night. I'm sorry, she was wrong also".

Story # 14 : "I Thought I Was Dying"

Sean ia a 19 year old male who was struck by a truck while he was riding his motor cycle. He received a lacerated spleen and a left fractured elbow as a result of the accident. He was taken by ambulance to the University Hospital were a Splenectony was performed and a cast was put on his left arm.

Sean had recently acquired his own apartment and was quite pleased that he was out on his own for the first time. He was working as a waiter and stated "I enjoy the restaurant business and would like to go back to school and study it".

Unfortunately the accident changed his plans because he was told he couldn't return to work for

three months. Since he couldn't afford to pay for his apartment without the income of his job, he reluctantly decided to give up his apartment at least temporarily and return to his parents' home.

Sean's girlfriend Kathy has been at his side throughout the hospitalization and only going home to sleep. She provides emotional support to him. Kathy is present during the interview, although she never speaks, just sits quietly and listens.

I FIRST CAME TO THE HOSPITAL .....

"I bought a motorcycle a couple of months ago and I got into an accident and they brought me here and operated. They .... because they had a trauma center here and I wasn't looking too good. They just brought me up here because it was right up the street. ..... The motorcycle is kind of banged up. I'm going to get rid of it. I got it in May and cracked it up the first day I got it and put in for an insurance claim and just got it back about a month ago, really three weeks ago. And here I am".

WHEN I WAS ADMITTED I FELT .....

"When I came in I was pretty groggy. They let me know what was going on."

(Do you remember riding in the ambulance? Were you awake through all that? Was it kind of scary?)

"No, it wasn't scary. Just having the accident was scary. After that, I knew I was all in one piece and all my parts were there".

"On the day of the admission they were telling me everything too fast. They took everything away from me once they took me to surgery. I was scared and shaking. The next thing I remember I woke up and it was over".

"The first day I was kind of gone to the world, that was the only time I was embarrassed, they took all your clothes off, they start throwing tubes in and out of you, like that. It was very systematic. It was very uncomfortable because I didn't know what was going on. They were telling me too quickly what was happening, what I did, what I ruptured, what was broken, what they would have to do in surgery, and it really scared me when they put me out. I have never been out before. They told me I'd feel a pressure and all of a sudden, boom. I couldn't see. My eyes were wide open and I couldn't see. I couldn't breath. All I could do with my body was shake it because I had no idea what was going on. I thought I was dying. I had no clue. I was not ready for that. All I could do was shake. Then I came to hours later. No control over my body. All I could do was shake".

"....Kathy has been with me, she understands what I'm going through. She knows there's a lot of stuff going in my head. Idle chatter, and its disturbing, very traumatic, when your body is wrecked. You know that everything on the insides isn't where it was two weeks ago".

"I'm kind of happy go lucky. I still have the use of everything. I've never been in the hospital before".

"It drags here. It has its high and lows. Nothing to do its just boring. Pain comes and goes but the medication solves it in a half an hour. Everything turning out well. ...All you can do is think".

A CARING EXPERIENCE IS .....

"Ya. There is a lot of... not sympathy, but most of the staff knows how it feels. Very understanding they know how its feels like getting needles and that kind of thing. They know its not your kind of fun. They are pretty good staff here. They are understanding. They know its not your choice. You don't have a choice. You are banged up and have to be here".

A NON-CARING EXPERIENCE IS .....

"Just in waiting. Waiting is the only thing that I really don't like. It's not so much that you are ignored, it's just a matter that they have so many people to get to before you and after all, so it's not like they're just holding you off, the person after me had to wait just as long as I did. It's pretty good.

None of them seem nonchalant. They all seem to take the job very seriously and are here for the patients".

MY RELATIONSHIP WITH MY DOCTOR(S) IS .....

"He´s (doesn´t know the name of his doctors, either surgeon or orthopedic surgeon) a patient doctor. He usually comes in in the morning with a group of doctors and talks about how things are going and what they are going to do. He tries to let me know what I´m in for and what is going on and what is going on for the day. He´s a nice guy. Well disposition, kind".

I FELT ..... DURING TEACHING ROUNDS.

"It´s a lot of..... ,because usually they have their own specialty. You know, an orthopedic guy comes in and he goes first on my foot, a guy asks me about my muscles, another stitches, another .... they let you know what is going on. They don´t say you´re fine, don´t worry about it. They will be putting me on whole food once I have a bowel movement with no problems. It´s working out really well".

(Have you ever felt they were talking to each other and not to you?)

"Not really, all the questions are generally directed at me. Once in a while one of them will ask one of the others about.... well, was it possible to do the x-ray on his shoulder? Should he be able to lift it?....."

MY RELATIONSHIP WITH MY NURSE(S) IS .....

"They change every day. Usually during the week its Kimberly but she has the weekend off. They´re all nice. Its nice to know your nurse´s name especially when you hear them on the intercom. Sally this room or that room. They are all generous, give you a hand with everything and help each other out".

"Kimberly is my primary nurse. It´s good because she has the most indepth knowledge of my case. There are a lot of things I´m confused about because I´m not a medical kid and she can put it in black and white. Its good to have one nurse that knows more because they can help you out".

"Kimberly is light hearted, easy to get along with. They´re all understanding to what I´m going

through. They are very opened and they don't avoid a situation, a question about this or that. Like I was having trouble having a bowel movement and they told me I may have a blockage in my intestines and may need to have another operation. I did not like the thought of that but everything went well. A lot of things they let me do on my own without embarrassing me.... I don't want anyone doing that for me. I'll do it for myself like taking a suppository. Thank you very much I can do that myself".

"They let me go off the floor to be with Kathy. They knock on the door before they come in. Is everything all-right? It isn't as if they just come and go at their pleasure. They are all very courteous. Like if one is in here doing my vitals and one comes in with an I.V., they say, I'll be back in 15 minutes, take your time. Its very comfortable. A lot more comfortable than I expected".

"So far at night I can't sleep" Sleeping medication doesn't help, so the nights are long and boring...."

"I've never seen an attitude problem with anybody. They're all been sympathetic. They are not really sympathetic, its more like caring, sorry they have to give you a needle, it's all for my benefit".

COMPARED TO MY EXPERIENCE IN COMMUNITY HOSPITALS.....

"A friend of mine was over at General Hospital and its depressing. One of my friends was in a motorcycle accident stayed there. It was a hellhole. This is like a country club compared to that place. It was very unkept. The rooms are ..... a lot of writing on the wall, magic marker on cabinets and stuff, little smears here and there.... This is clean, its tidy, it looks better".

"It's set up to help you get your independence back. I have to relearn everything all over again. It keeps you in touch with you body".

Sean refused to participate in the second interview once he got home from the hospital.

Story #15 : "I Needed the Attention I Was Scared"

Alice was admitted for a pericardectomy, removal of the pericardial sac that surrounds the heart. She has been suffering with pericarditis and pericardial effusion for the past four months. She has not responded to medication. The pericardial effusion was creating a constricture of the heart. She was unable to walk upstairs and became dyspneic with the slightest exertion. She requires three pillows to sleep-due to othopnea and has a persistent dry cough. She recently had a weight gain of 10 pounds inspite of her anorexia, and increased fatigue. As her condition deteriorates she begs her doctor to do something for her to improve the quality of her life.

Past history reveals an insertion of a pacemaker eight years ago and a chronic irregularity of the heart called atrial fibrillation.

Alice is a retired accountant who is active on several community boards including a local community hospital board of trustee. She is comfortable conversing with health professional from her board involvement as well as having a brother who is a physician. He has becomes her resource for answering many of her medical questions.

Alice lives in the small New England town with her husband, who is a retired policeman. They have lived in this house for the past twenty five years. Her daughter is a professor in a well known Ivy League College and her son lives with his family in California.

Alice likes to be busy all the time. She is presently taking courses toward her college degree, something she always wanted to finish. The birth of her children interrupted her college education, so she decided to complete it now that she was retired.

I FIRST CAME TO THE HOSPITAL...

"My heart doctor, who I admire and have a lot of confidence in, suggested we try and find out what is going on and the cause behind the fluid around my heart. So we started a series of tests. I had an Echo, Pulmonary, ect They couldn´t find any reason and it was getting more painful". (All these test were done on an out patient basis.)

"The Echo and Cardiac cath showed the accumulation of fluid around the heart. During the catherization they drew off three quarters of a cup of fluid. Now I have asked my doctor and my brother, who is a doctor, how much fluid does a normal person have? And they said one tablespoon. They said there was a quart more fluid left. So what was happened it was constricting my heart. So he (cardiologist) confirmed what my own doctor diagnosed. So he sent me for a consultation with a Pericardial Fellow (expert). He confirmed the diagnosis and he suggested the complete removal of the pericarium".

"The question of whether I should only have a window inserted in the pericarium to withdraw the fluid or a complete removal of the pericarium became the issue discussed with various specialist involved on my case. The doctor first sent me in for a thallium stress

test to evaluate my cardiac output. I had a cardiac catherization at General Community Hospital by Dr. S."

WHEN I WAS ADMITTED I FELT...

"Meanwhile time marches on and I'm uncomfortable waiting for their decision on what to do. Finally, one Sunday I decided I was too sick to go to church and asked my husband to drive me to our family physician. I can't breathe, I can't swallow. He took an EKG and admitted me to the hospital".

"I was scheduled to have surgery on Thursday and be admitted on Tuesday but it became so bad I was admitted on saturday. So first the decision was to lean toward the window. And I said if I have anything to say in this matter, which I probably don't, if you are going to do a window I'm going to be back I'm sure. They had told me that once a person has their pericarium removed they can live without it like a person can live without their appendix. I said please go the route, I just can't put up with it. And so that is what happened".

A NON-CARING EXPERIENCE IS ....

"This nurse questioned why I am using the spirometer so frequently." (This is a device that requires the patient to blow air into a tube that pushes a ball. The purpose of this exercise is to assist the lungs to expand and prevent atelatisis.).

"She tells me it's going to cause more damage than good. I tried to tell her the doctor told her to use it. But all she does is scold me and told me you are only suppose to use it once an hour and three times a day."

"I'm confused at what I'm suppose to do. I certainly don't want to damage my heart but the doctor told me to use it this way. So the next day I ask him and he tells her I'm right and not the nurse. In fact he goes on to say that I'm one of the only patients who is using it appropriately . How do you trust the nurse or believe she know what to do? "

"I'm left with a feeling that I have to question everything. But I don't know enough to question everything. It makes me feel uncomfortable".

"The care down here (surgical unit) needs something to be desired.

(What made the care so different between these two units?)

"For one thing I guess they had more time. Down in this area the patients are much sicker and demanding of care, whereas upstairs we were... they were watching our telmetry careful about it. Believe me they were careful about it. I just felt there was time to take care of patients. Now, I don't think they have over staff but it could also be that I didn't need as much care. But down here to me ,I don't known. I would call on the button and she'd say that she would come but she doesn't. The problems is that I have tubes in me and I couldn't do anything for myself. I was told not to move and I can't raise my arms so I needed the bedpan. And he wanted me, Dr. B.(cardiac surgeon) wanted me to void as much as I could. I wasn't drinking anything because I couldn't get the attention. As a rule I' m not a complaining person, but I will tell you there are nurses and there are nurses".

A CARING EXPERIENCE IS ....

"And the care I received in this hospital on the sixth floor was unbelievable. I had an Indian doctor that just went out his way to see that I got everything. So the closer I got to surgery I found I had to have another Echo done. At that time there was a question that I may have an abnormality on part of the aortia so I had to have a CAT SCAN. So if I can't have a CAT SCAN no surgery"

"Now the CAT SCAN is a 24 hour deal, so each patient come in there on a basis. Well this doctor say Alice you're get your CAT SCAN done. Well I don't know how he did it but they pushed me in for a CAT SCAN that night".

"Everything went well. But the care, and the care I got up stairs before surgery, was what I would call good hospital care. After the surgery I was brought into the ICU and they were marvelous. Especially one or two nurse who really worked. The care was excellent. Kathy was was my nurse in the ICU and she was so great".

MY RELATIONSHIP WITH MY NURSE(S) IS ....

"The nurse I've had here most of the time is a lovely girl, lovely girl. Newly married,. very thin, constantly tired, just barely getting along. So the night nurse I started to .... In the evening I asked one of the nurses to walk me, Dr. B. told me he wanted me to walk. So I asked the nurse and I walked and I felt like a different person. I don't mean to be critical, but I do know that some of the nurses do more and are willing to do more. This nurse I had during the day came when she was good and ready, and the nurse I had in the evening had time to do things and talked to you. She even had time to talk to one of my neighbors. She was smilely and bubbly".

"When I was upstairs I was more independent. I also noticed a different attitude among the nurses. My roommate would call for the nurse if she needed one. That was comforting. I didn't feel alone."

NURSES ARE NON-CARING WHEN THEY ....

"I would say that the majority of the nurses are good but there are some just ....I tell you what is wrong there is too much time giving reports to each other. Somehow it would almost seem as if what was recorded the next nurse coming in would almost be able to and then if there was anything unusual. All I can hear is 'they're giving reports. They have to give reports. They'll be in later'. It seems as if there is these constant reports".

"Unfortunately I'm totally dependent upon on the nurses. I'd like to do more for myself but I can't with these chest tubes in place. I'm afraid to drink too much fluids because I can't get to the bathroom myself. I'd like to walk more but I can't do it alone because of the Chest tubes in places. I have no faith that they will be there if I really needed them. It's scary".

"The personality of the nurses are lovely but some just do more. Maybe they thought I was calling too often. I tried not to, but if you are sitting on a bedpan for an hour, I don't think that is right. That happened on two different occasions, and it wasn't that I didn't buzz. That is really the only negative part."

"My tubes have been out for the past twenty-four hours. I can now get out of bed myself. The nurse helps me with my cardiac rehab program. She has to take my BP and pulse before I start each exercise, so I can't

begin my exercise on my own. But it´s a much harder experience that I anticipated having surgery. I never had surgery before"

MY RELATIONSHIP WITH MY DOCTOR(S) IS .....

"It´s a caring relationship. I have a supportive and nurturing relationship with my own doctor(primary care). I really like my cardiologist and surgeon."

COMPARED TO MY EXPERIENCE IN A COMMUNITY HOSPITAL...

"I found the nurse at the community hospital were more caring. I was impressed with the nursing care on the medical unit and the technology at the University Hospital."

The second interview took place in Aloce´s kitchen. The house is situated in the middle of a steep hill. She appears to be thinner and more relaxed than she was in the hospital. Alice had her bedroom moved down stairs so she wouldn´t have to climb the stairs. She started driving her car and comments on how she

> feels more independent. I likes being thinner so I´ll stay on a low caloric diet. I´m looking forward to having Thanksgiving dinner with my family, they are all coming home for the holiday.

AFTER I WAS DISCHARGED.....

"Dr. B. (surgeon) knows what he is talking about, when I was discharged that it would take about a year for all the healing to take place. He said don´t lift anything heavy and use your common sense. I have a problem with closing the garage store or closing big church doors they are too heavy."

"What does it do to your stomach when you take so many drugs? It seems like I´m taking a lot of drugs but everytime I ask the doctor about it he says not to worry but it seem like a lot of medication."

"The lungs are clear. I have no complains. Everyone has been good to me. But, I´ve noticed I get tied and need a nap in the afternoon".

MY REFLECTIONS ON CARING.....

"I tries not to make hasty judgments of people. Tries to evaluate them based upon multiple encounters and to be forgiving and to understand why people behave the way they do."

"I did notice a difference between the values and attitudes of the older and younger nurses. Older nurses appear to" like being a nurse and have come to the conclusion that the shorten length of stay has contributed to the nurses´ attitude to being indifferent to patients. Not able to establish a relationship because the stay is so short".

"Of course I was there 15 days; three upstairs, and the rest of the time downstairs. They were probable tied of seeing me, and they probable didn´t realize that I had those tubes and couldn´t get around by myself. It wasn´t that I needed so much care but if they had taken out those tubes I could have been more independent. They didn´t take those tubes out for eight or nine days, so I needed the attention. I just couldn´t just get up and go to the bathroom. Oh, some of them were good...the night nurses were good. But the day nurses.... some of them were good".

(When I mention the word "caring" does that create an image of the nurse?)

"Well yes, it would have to. Absolutely, they are the one who is there 24 hours".

"I couldn´t ask for two better doctors. When I did have to go home I asked him if I could stay that extra day and so he said sure. He said, are you sure you want to go home saturday? If I wanted to stay an extra day he said it was o-k.

"The Indian doctor was great. In contrast I found the physicians were more caring".

"The nurse who was newly married was the only one who I thought was poorest nurse. I recall an incident when it was brought to her attention by the doctors that she was not doing the correct thing with the needles ....but I heard him say to her, you shouldn´t be handling a needle like that".

"Perhaps she was just too tired being newly married and all. I really have forgiven her, and I should be more understanding. Maybe they expected me to do more for myself. But I couldn´t. "

"But I found the nurses on the 6th floor were more compassionate... they drop by and see how you are without being buzzed; they answered their... likes more timely. They were interested in us as people. They made you feel as if they wanted to help you. They would explain where they were going and when they would be back. The attitudes were different".

"They (MD) were a team. They wanted me to go home. But it was my own doctor that I think of. When they sent me home they were wondering if I had some drainage. He (primary care doctor) wanted to see me in just a few days. The team seems to be the difference between community and the teaching hospital".

"Two of my doctors differed in their opinion on what medication I should take post operative. I became the one who transmitted the information. But the my own doctor (primary care) disagrees."

"My doctor (primary care) didn´t want all the pre-admission test. Cardiologist and other doctors at the University wanted to do all the tests. Each an every one of them throughly and throughly examined me. I think they were caring. What one didn´t know, the other knew and they used each other knowledge to determine together what was in my best interest".

CHANGES I´D LIKE TO SEE IN THE HOSPITAL TO MAKE IT MORE CARING

"Only the nursing care on the surgical floor. Perhaps they perceived me as a chronic patient and not as sick as some other patients and that is why the nurses failed to pay attention to my needs".

"The night nurses were more compassionate but they were older nurses. Maybe that was why they were more compassionate".

(Did you notice that on the 6th floor as well?)

"Older nurses do it for the love of nursing. Oh I noticed it right away".

Story #16 : "The Wise Old Owl"

Elie is an 84 year old retired school teacher and principal. He has written and published children's story books in which he also did the art illustrations. He lives in a small New England town in a state north of the the University Hospital.

This is the second marriage for both Elie and his wife. They were married thirty years ago after Elie's first wife died and Margaret was divorced. They live in a third floor garden apartment not too far from their adult children. Margaret is also a former school teacher, so the two of them enjoy discussing and reminiscing about their teaching days.

Margaret is devoted and attentive to her husband's care. She stays at her husband's bedside the entire waking hours of the day while he is a patient in the hospital. She has found a local bed and breakfast near the hospital while Elie is a patient at the University Hospital. She attends to many of his personal needs for bathing and toileting.

Elie has been in relatively good health until the last few years. At that time they found he had advanced arteriosclerotic vessel disease and performed a

coronary artery bypass graph a year ago. The doctors also found an aortic aneurysm but chose to wait and monitor its size closely rather than take the risk of performing two major surgical procedures together. During the past years the aneurysm had increased in size to 5.8 cm. so Elie was once again admitted for repair of the adodominal aortic aneurysm.

During the interview the wife played an active part in the interview process. Her perceptions as well as Elie´s are noted in the following story.

I FIRST CAME TO THE HOSPITAL .....

Wife: "It was the reputation of the Medical Center that attracted us to the Medical Center. Our daugther-in-law is a nurse and she contacted a physician
she knew and he recommended Dr. C."

A CARING EXPERIENCE IS.....

Elie: "A caring environment, oh yes, very thoughtful. Now and then I see something that I don´t like but it´s human nature and you can´t do anything about it. I thought it was a highly enlightened caring environment. You have to wait for a bed pan for a half an hour sometimes, but its an economic matter. They are short of help.....you can´t get the help with the wages they are paying to do the job. And I haven´t seen any prejudice against psychic healing around here although I haven´t gone into it here."

(Could you explain what you mean by psychic healing?)

Elie: "It´s what they use in Eastern Medicine .... It´s using their spiritual powers to heal. Western doctors underestimate their healing powers".

I"VE NOTICED ..... CHANGES IN CARING OVER THE YEARS.

Wife: "Discharging too soon, that is a definite change than what took place years ago. After the heart surgery he was sent home to K. (town) but ended up in the community hospital because he had a reaction to the medication that he was sent home on. When he went home he was as shaky as he is now. He went home too soon".

Elie: "Medication made me hallucinate I felt so terrified. I never felt so terrified .I never experienced anything like that".

(How did you get home if you felt so weak?)

Wife: "Oh they arranged for an ambulance, but he was really too weak to go home.

"When I had a caeserian section (years ago) I had a private duty nurse that just gave me back rubs and was there at my beckon call. Gone are those days. I understand that if you need a nurse and you are really sick the nurse is there. But not like it was year ago".

MY RELATIONSHIP WITH MY DOCTOR(S)IS .....

Elie: "Oh yes he is (caring) at first I thought he wasn´t.... strictly professional. But as the experience grew I changed my mind. He is very technically competent. I noticed a change in his attitude ... after a while he became more personable. He has been watching over me for a whole year".

Wife: "We knew the aneursym was being carefully watched and we knew when it grew in size that Dr. C. was there. That was a nice feeling. He was all set a year ago (for surgery) but he had the open heart surgery a year ago".

I FELT .... DURING TEACHING ROUNDS.

ELie: "They´re amusing. They (residents and Dr.C.) walk in and out of the room in formation with the big guy (Dr. C.) in the lead. They look like duckling following the mother duck. They (residents) rarely talk and wait to each takes their turn listening to my chest or examining me"

(What do you do during this process ... do you feel apart of it?)

Elie: "Oh I just watch in amusement. It easy to see they (residents) have great respect for Dr. C.

Wife :" Oh it´s not that Elie they are just being courteous to him as they enter and leave the room."

NON-CARING EXPERIENCE IS....

Elie: "No never. They are professional, charming, curious to requests or questions".

Wife:" Well there was one time he was out of bed for the first time. I thought he was out of bed too long and kept going out to the desk. Later I found out he was suppose to be out of bed that long but no one informed us. Would have appreciated being informed that he was supposed to be out of bed that long. I was doing all that unnecessary worrying and I felt foolish running out to the desk so often when it apparently wasn´t necessary."

MY RELATIONSHIP WITH MY NURSE(S) IS .....

Elie: "They call me Elie and I like that. Nurses are friendly. Some are outstanding. Just the desire to serve... desire to do their job and do it well."

Wife: " Well I don´t like to hear him being called by his first name. But there is one nurse Laurie who has such an air of competency. She comes in and she has a hold of the situation. It just make you feel so ... it´s such a nice feeling. It´s wonderful and you feel in safe hands".

Elie: "Some are just born nurses".

NURSES ARE NON-CARING WHEN.....

Elie: "I had one nurse she was abrupt and had a poor attitude."

MY EXPERIENCE DURING DIAGNOSTIC TESTS WERE .....

Elie: "Not that pleasant but they were caring. During the angiogram I talked to an interesting man. I think he was Russian."

CHANGES I´D LIKE TO SEE IN THE HOSPITAL TO MAKE IT MORE CARING

Elie : "I´d like to see them (doctors and nurses) use the therapy of spititual meditation so that they

would become in touch with their own powers of spititual healing".

The second interview took place in a small den overlooking a garden. Elie looks content to be in his own surroundings. His works of art and his books which he has published are proudly displayed in the room. He enjoys the tranquility of this peaceful country setting. The small wooden plack on the door is a picture of an owl drawn by Elie. His wife thinks this describes Elie, "the wise old owl".

AFTER I WAS DISCHARGED.....

Wife: "Elie came home from the hospital in an ambulance. The drivers carried him up to the apartment (third floor apartment). Unfortunately the infection (urinary tract) was not completely gone so he had to urinate constantly and was up most of the night."

"Constant use of the urinal. I understand it was caused by the infection (urinary trait), and they couldn´t be in the room all the time.(referring to the nurses in the hospital). But it was here (community hospital) that they cleared it up by finishing the antibotic that were prescribed at the University. I guess it was just working out of the system and I understand it is common to have a urinary tract infection with a catheter".

"The day after he was home he started to complain about difficulty breathing and began to gasp for air. The VNA nurse saw him that morning and took his blood pressure and pulse. She told us there was nothing to worry about. That night Elie couldn´t breath lying down. I knew there was something desperately wrong with him. Finally in desperation I calls our daughter-law (nurse)".

"By the time she got here his breathing had developed a "rattling" sound and his color was like putty. She took charge of the situation and immediately calls an ambulance. My daughter in law saved his life. He was literally drowning in his own secretions."

"I don't know if it is their fault or not but the medication they prescribed just wasn't working on Elie".

"I don't understand why the VNA nurse didn't call the doctor. She took his blood pressure and his pulse and said he was o-k".

"I was worried sick all night and I didn't know what to do. I knew something was wrong but the nurse said there was nothing to worry about and the doctor was out of town for the week-end".

"He ended up in the ICU (nearby community hospital) and was there for the next 24 hours. It is there that they discovered his medication was not regulating his cardiac rhythm. The doctors there gave him a different medication to control his heart."

"I'd rather have had him stayed in the hospital longer and given up the VNA nurse. What good is she anyway? Oh she was sweet and pleasant, I don't mean that, but what good was she anyway?"

MY REFLECTIONS ON CARING.....

Elie: "He (Dr. E. his primary care physician) seem more interested in his patients then many of them do. He listens to what you have to say so when you talk to him. You know he has the overall picture and he is quick to refer you to somebody who knows more about it than himself. He has a good technician, her name is Sandy and she takes a lot of tests. He doesn't hesitate to call someone in when it is needed. Pleasant fellow"

Wife: " He's conscientious, and caring".

Elie : "Dr. C. (surgeon) is very profession. He is very much the surgeon. He has the technical end of it and leaves the rest of it up to others."

Wife describes him as, "knowing he belong to the top echelon; he is a surgeon."

Elie is more direct and states "I'd say he is impersonal"

Wife: "Yes there is a little distance between him and the patient."

Elie : " Dr. B. (surgical resident) had little to say, just trailed after the big boy" (surgeon).

Wife : " Now Elie don´t you remember how he came in every day and checked up on you without Dr. C.. Perhaps he is the one who failed to prescribe lasix. He is the one who decided on the medication."

Elie : "He was kinda a friendly fellow. I liked him. The hospital was strictly impersonal. I never experienced anyone as being unkind or discourteous. I would have to wait as long as fifteen minutes for the nurse. I don´t know... they say they are understaffed down there but they don´t complain down here (community hospital). It´s a more social and stimulating environment. They don´t hesitates to make a funny joke or tell a little story..... Waiting was the thing that was upsetting. I could never find the call button. If they would only attached it in the same place maybe I could have found it."

Wife corrects him and says "they weren´t like that down there Elie, don´t you remember how friendly Kathy was?"

Elie: "Oh I don´t know when I´m going to see her again."

Wife: "You can´t compare an ICU with the surgical unit. The number of nurses was decidedly different in the two units".

MY REFLECTIONS ON NON-CARING.....

Elie describes his experience of being intubated while in the ICU in the community hospital. "It´s a frightening experience. It felt like the (endothracheal) tube was slipping out of my throat and I couldn´t breath. I was gasping every minute to breath. I tried to push the tube back into place with my tongue and tried desperately to communicate with the nurse but I couldn´t because my hands were tied down and I couldn´t speak with the tube in place."

Wife: "I could see he was restless and I tried to reassure him he was going to be all-right. The nurses told me that all patients try to pull out the tube so they had to restraints his hands. I tried to explain to him what was going on and to get Elie to relax but he just couldn´t relax.

Elie: "I couldn´t. I thought I was going to die."

CHANGES I"D LIKE TO SEE OCCUR IN THE HOSPITAL NOW THAT I"M HOME.....

Elie : "I´d make me well so I wouldn´t have to go to the hospital."

Wife : "I´d change the insurance (medicare). I ´d have a system that the initial place that gives you care would follow you through until you were done. Now when your insurance is up out you go unless you are willing to pay $600 a day which many people can´t do. It doesn´t seem like they should be so strict between this hospital and that hospital".

"I just found that I could have appealed during the initial 24 hours of being told that the insurance coverage had ended and Elie had to go home unless we wanted to pay for the hospitalization. We weren´t told that or given an alternative. They kept him two weeks this time, that was twice as long as they did after the first surgery, so I felt I couldn´t complain. But it was his second surgery, and he is another year older".

Elie : "When the Greek Giant was lifted up off of earth he lost his strength but when he had his feet on the ground he gained his strength. He was finally defeated when he was held up in the air and he finally expired. So when you have your feet on your own home rug you get far. That´s the way I feel about it".

Wife : "Its an enormous team, the cardiac group, the vascular group, or whatever it is . So many hands spoil the broth I think. I don´t think one knows what the other is doing and it is such an enormous task. You have to have teaching hospitals"

"Nursing is very meticulous about explaining the medicines what they are for, how often you take them and questioning if you understand".

"For one thing I hope we don´t have to go back to any hospital. Not to have the aneursym hanging over him is wonderful. I don´t have to worry about it, for that, I am grateful."

CHAPTER 5

INTERPRETATION AND ANALYSIS

Introduction

Interpretation and analysis of data collected are presented in five sections, caring, non-caring, emerging hierarchy, community vs academic teaching hospital, and comparisons of patients current caring/non-caring experiences with their previous experiences of five or more years.

The researcher was unable to analyze the relationship between severity of illness and the patient's interpretation of caring or non-caring, since 72 % of the sample population were severely ill. This study, therefore, is biased in favor of patients who have had life threatening experiences. The sample population, however, is characteristic of patients found in an academic health care center.

The first section analyzes caring experiences of male and female patients. Five metaphors are used to analyze and interpret data which have evolved from the patient's description of caring. Comparisons and analysis are made between female and male patients' interpretation of caring.

Section two presents non-caring experiences by using four metaphors in an attempt to capture the essence of these experiences. An analysis is made between male and female patients' interpretation of non-caring events.

The researcher found the emergence of what appeared to be a hierarchy of caring needs. Although this was not part of the research study, clinical impressions suggest that patients may rank their expectations for the care givers in a hierarchy. That is, the data suggest that there are categories of caring behavior that must be met before patients perceive care-givers as caring, regardless of how attentive the care-givers are to other categories. However, more research is needed to study and validate the existence of this phenomenon. Section three presents a brief analysis of these findings.

The fourth section compares and contrasts the caring and non-caring experiences in an academic health center with those experiences described by patients in a community hospital.

Caring and non-caring experiences noted by male and female patients in the past five or more years are compared in the last section.

Metaphors Which Describe Components of Caring

There are five metaphors most frequently expressed by patients to describe their caring experience. Caring is:

- TREATING ONE LIKE A MEMBER OF A FAMILY.
- TREATING ONE AS A PERSON NOT A PATIENT.
- PUTTING ONE BACK TOGETHER
- UNDERSTANDING HOW I FEEL
- GOING OUT OF YOUR WAY.

Caring Is Treating One Like a Member of a Family

The metaphor TREATING ONE LIKE A MEMBER OF A FAMILY was used by 31% (5) of the patients. It portrays a picture of the patient being cared for in much the same way the patient experienced caring at an earlier stage of his/her development. It creates an image of the physician and nurse as parents responsible for the well being of a child. The concept of nuturing, protection, and surveilance (watching over them) make up the ideology of the family unit along with a sense of being loved and protected from harm or injury.

"They make you feel like part of their family.... they care so very deeply" Marion said.

The metaphor also conveys an image of the authority figure being the doctor (father) and the nurse (mother). It portrays the patient in a subservient and regressive role of a child. Marion, a 69 year old woman, articulates that she was brought up to "so highly respect authority figures" and that she is afraid to ask the doctor questions. Nancy on the other hand, a 26 year old college educated professional woman of the nineties, resents being treated as a child. The data suggest that if women have been educated and socialized in an environment which accepts women being assertive, they will become more assertive in the doctor and/or nurse patient encounters. The contrast between Marion's view of the hospital and Nancy's view clearly shows the influence of education, social background, family relationship, and the era of their times. Patients bring to the hospital their understanding and perception of the world around them and their role within it. Female patients like Nancy and Betty who are comfortable with their own self image tend to seek knowledge about the medical care plan and expect to be treated as an adult member of the family unit. This is also true in Rose's case, an assertive

woman who attempted to play the role of the mother directing her son, Dr. F., whom she loved and trusted.

Factors which seem to influence the patient's acceptance of a passive role are age, sex, education and socialization. Sam, a middle aged college graduate, wanted to be in control of "his own body " in much the same way as Edward and Paul. Male patients tended to be more assertive in their demand for knowledge about their care. Younger male patients such as Sean and Keith, who were still in a dependent relationship with their parents, tended to transfer the parent role onto the doctor and nurse. If the nurse or resident physician were closer in age to the younger male patient, their role took on the characteristics of an older brother or sister.

The physician and nurse played different roles in the family unit; a brother, sister, daughter, son, mother or father. The age and sex of the patient and the care provider seem to influence the role which the patient ascribed to the provider. Mary, who is a middle aged woman, saw her doctor as her younger "brother". She was comfortable knowing that her physician was concerned about the high probability of her death, and what would happen to her son when she died. They were

able to communicate their feelings in much the same way two siblings would exchange concerns and fears about their life and future.

Rose on the other hand commented that she didn't "know who was the father" when she was describing the relationship between her husband and the male nurse who was caring for him. Thomas saw Sandy (nurse) as his daughter when he commented, "Sandy kissed me goodby like I was her father." He was emotionally touched by this gesture, especially since the kiss conveyed she had similar feelings of affection and concern about his welfare, in much the same way a daughter would kiss a father goodby.

Family members are expected to be there when you need them. They are not acquaintances who come into your life and then disappear. They are not strangers. They are expected to accept you with all your weaknesses and frailties. Marie, a young Hispanic single parent describes her son's neurologist as someone she could go to with "all her problems". He was there to help her solve her social as well as her health problems, like the time he helped her and her children find shelter when they were homeless.

Most patients commented that they liked having the same nurse every day. Nancy commented on how difficult it was to bond with a nurse or doctor because the opportunities for interchange or communication were often brief or because assignment of nurses or doctors were inconsistent. In cases where there was an opportunity for continuity of care between the nurse or physician there was a bonding between the patient and care provider. This was also seen in the story of Dorothy, a patient with Leukemia. Many times she was reluctant to express her fears about her disease or death, or to ask what she called "anxiety type questions" to a new nurse, but felt comfortable sharing these feelings with her primary nurse who was assigned to her each day. Similar feelings were expressed by Marie, John and Edward.

Frequently patients commented that they were confused about what the doctor was saying to them, but were comfortable asking the nurse to interpret this information for them. Thus, the nurse served as an interpreter of the medical care plan. This reluctance to question the doctor and to refer these questions to the nurse may also reflect communication patterns within a patient´s family unit or their comfort communicating "feelings" to females since the majority

of nurses are female. It may also reflect an embarrassment to admit that the patient didn't understand the doctor (male parent).

Although female patients tended to describe care providers with whom they had not established a relationship as non-caring, male patients did not. However, male patients expressed a higher degree of satisfaction with their care, if they had established a relationship with their nurse or physician. John, who had been a patient many times in the past fourteen years due to his chronic and debilitating disease, spoke of Dr. Z. with love and affection. This special relationship was developed through many years of medical follow up by Dr. Z. The physician was able to communicate complex medical jargon into simple language that John could understand. He became his intepreter of not only medical language, but of his covert feelings and fears. John expressed his frustration with not being able to have a primary care physician follow his care. But Dr. Z. was a specialist who took a "special interest" in John and acted as a buffer for him with the other medical specialities who were involved in his complex care. When John was asked what he would change to make the hospital more caring, he commented:

> The ideal situation would be to have one doctor and nurse .....it would be like a mother and father almost.

Caring Is Treating One as a Person Not a Patient

The metaphor CARING IS TREATING ONE AS A PERSON NOT A PATIENT is used to suggest caring as being personalized rather than being depersonalized, as the "gall bladder (or heart) in room 304". Both male and female patients (81% or 13 patients) expressed this metaphor as descriptive of caring. All patients wanted to be seen as individuals treated with respect and dignity.

> Here everyone knows your name .... They call you by your first name. It´s nice that they remember you by your name.

"People make you feel that you are important" and that they genuinely care what happens to you. Marie clearly expressed these feelings. She was able to articulate how she felt when she was treated as "a person". It was different than being treated as "a patient". It is knowing that the doctor sees you as a person with feelings, fears, family concerns and social problems. It speaks of a holistic view.

Personalization of care requires the care provider to know and understand the personal characteristics and needs of the patient. Nurses and doctors who allow the patient to participate in decisions which affect his/her care and who listen to what the patient is saying and not saying, are able to personalize the care.

> Here the nurses ask you when you want to wash up... not routine that everyone must have a bath in the morning.

Caring Is Understanding How I Feel

The CARING IS UNDERSTANDING HOW I FEEL metaphor was expressed by 37% (6) of the patients. It conveys the ability of the care provider to communicate empathy and understanding of what the patient is experiencing. The patients want the doctor and the nurse to accept them and their mood swings. Patients experience the various stages of death and dying noted by Kubler-Ross (Kubler- Ross, 1975), therefore, moods swings are common with persons with an illness. All patients in this study expressed thoughts and ideations about death and dying, and the recognition that they are or were vulnerable to death at some stage in their illness or hospitalization. Feelings of anger, despair, sorrow, shock, denial and reassessing their life style, were part of the process of their illness. Patients want and need the doctor and nurse to accept their outbursts of anger, and not to interpret these as personal attacks. When care providers are able to convey this acceptance, it is seen as caring behavior. Peter expressed these feelings when he said:

> Their (nurses) attitude is nice. They come in here and I´m in a shitty mood and they don´t snap back at you (me).

In Sam´s case his angry acting out alientated him from the surgical staff. He was labeled as a "difficult

patient" and one who staff tended to avoid. Many physicians failed to understand his cry for help. He was frightened and scared that he would be paralyzed or die. He didn't know anyone at the Medical Center, nor did he know why he was taken there. He didn't know whom he could trust. To begin with he had not had the opportunity to select his physicians since he was airlifted from a community hospital to the Medical Center. It was not until Dr. G. "took the time to explain" the rationale for the tests and his medical plan of care in detail that Sam's outbursts of anger began to dissipate.

Male patients in this study were more comfortable expressing their anger than female patients. Female patients tended to repress these feelings as we saw with Alice. Even though intellectually she knew her anger toward her primary nurse was appropriate, she continued to forgive her and questioned what she had done to make her not want to care for her. It was as if she felt guilt for having any feeling of anger. Although Rose was able to verbally express her anger about a non-caring nurse, she became physically shaken when she recalled the experience weeks after the incident.

Female patients appeared to be more comfortable expressing their fears to a care provider with whom they had established a relationship. In contrast, male patients rarely verbalized their fears in spite of the fact that they had experienced life threatening injuries and illnesses. Their fears and concerns were expressed in covert expressions and behavior.

Caring is Putting One Back Together : The Power to Heal

The CARING IS PUTTING ONE BACK TOGETHER metaphor captures the image of caring as curing, healing, and relieving pain and discomfort. It implies competency and ability to heal and put the patient back together again. Although nurses provide relief of pain and discomfort, all of the patients (100%) attribute the curing abilities of the physician as caring and unique to the physician.

The use of other experts in diagnosing and treating patients was seen as examples of caring.

> Each physician thoroughly and thoroughly (completely) examined me. What one didn't know the other knew. They used each others knowledge to determine what was in my best interest.

Patients perceive the use of many diagnostic tests as a sign of caring. S(he) is unable to judge the physician´s competency. (S)he uses the reputation of the physician, to evaluate his/her competency in much the same way as Peter did in selecting Dr. S. as his orthopedic surgeon. Peter and Elie accepted their physician´s lack of bedside manner and poor interpersonal skills as long as he was competent to put them back together.

Female patients are more accepting of a lack of competence if the physician/ patient relationship is supportive toward them. This is seen in Betty´s case when she stated the reason she didn´t sue or blame her physician for her chronic degenerative bone disease, even though she knew it was caused by a failure to properly monitor her steroid level, was because "he was caring and concerned about my daughter".

Nurses are seen as the ones who relieve pain and discomfort. They are the around the clock care providers. Relief of pain is seen as caring, and ignoring the patient´s pain or failing to relieve pain is seen by both male and female patients as non-caring.

Caring Is Going Out of Your Way

The metaphor which seems to best capture both male and female experience, is GOING OUT OF YOUR WAY. This metaphor was expressed by 75% (12) of the patients and characterizes the need of the patient to feel important or "special". Patients accept and understand that nurses and doctors are busy caring for other sick patients, but if the care provider goes out of his/her way to help a patient, the patient interprets this as a sign that the nurse or doctor genuinely cares about them.

Rose refers to "the little things that mean so much" throughout her interview. She felt like a queen or a member of royalty by the way she was personally greeted in the E.R. by the surgical residents. It is the" little things" that convey a message that the nurse or doctor cares, like physicians telling the patient when they are going away, giving the patient the physician´s home phone number, returning phone calls, visiting them in between other activities of the day, sharing personal opera tapes with the patient, or cutting through the bureaucratic red tape to get the patient´s room transferred, or a test performed.

Patients do not want to feel that they are bothering the nurse, so they try not to call unless it is important. The expectation, however, is that the nurse will answer the light right away. When nurses reassure patients that the patient is not bothering them, that behavior is seen as caring. Nurses who provide frequent surveillance by visiting patients, or asking if they can get something for the patient without being called by the patient, are always seen as caring and going out of their way.

Sam tells a story of waking up in the middle of the night with chest pain, and a male nurse, sensing he was frightened, stayed with him until he was comfortable. According to Sam, he "took the time to make sure I was o-k". In short, caring, in large part, is seen as behavior that conveys to the patient a sense that the care giver sees beyond the patient to the thinking, feeling and vulnerable human being that exists.

Metaphors Which Describe Components of Non-Caring

Four metaphors are used by patients to depict their non-caring experience:

- ABANDONMENT
- LACK OF COMPETENCE
- SHAME AND HUMILIATION
- NOT LISTENING

Non-Caring as Abandonment

The metaphor NON-CARING AS ABANDONMENT conveys an image of patients who felt forsaken or deserted by the care provider. It was expressed by 75% (12) of the patients. The patients feel demoralized, shameful, and began to question why they were not important to the care-giver. Abandonment takes on many forms in the experiences of patients.

Alice felt abandoned by the nurses who left her on the bed pan for hours, and consistently failed to answer her light. She became so concerned and frightened by this experience, that she refused to drink water even though the doctor had stressed the importance of taking fluids. The fear and shame associated with the thought of wetting her bed was greater than her need to take fluids.

> Unfortunately, I´m totally dependent upon the nurses. I"d like to do more for myself but I can´t with these chest tubes in place. I have no faith that they will be there if I really need them. It´s scary.

There are a variety of care giver behaviors that generate abandonment feelings in patients, including failure to treat pain. Betty describes how she felt when the physician told her not to come back until she couldn't walk anymore. His refusal to treat her while she was in pain and discomfort was seen as abandonment. "He didn't give a damn what happened to me".

John described a similar incident which involved a resident and intern. In this case, the patient felt he had unnecessary pain and discomfort during a thoracenthesis because the resident placed greater priority on teaching the intern than on the comfort of the patient. John felt that when the intern was unable to draw off the fluid on the first attempt, the resident should have completed the procedure. Instead the resident allowed the intern to make repeated attempts at the patient's expense and discomfort. Failure of a physician or a nurse to relieve discomfort when they have the ability to alleviate pain and discomfort is seen as non-caring. This was expressed by both male and females and is not gender specific.

Non-Caring as a Lack of Competency

The metaphor NON-CARING AS A LACK OF COMPETENCY was expressed by 63% (10) of the patients and

emphasizes the inability of the care provider to protect the safety and well being of the patient. The patient lacks the technical knowledge to evaluate the competency of the physician or nurse, so s(he) must blindly trust that the care providers will provide safe and competent care.

Marion describes how she lost trust in her gynecologist's ability to protect her. She had had a prolapsed uterus for over twenty years and refused surgery. She became frightened when she found herself hemorrhaging in the middle of her bathroom. How could she go back to him. He never told her this would happen. What if she had cancer? All these "scary thoughts" were racing through her mind. She didn't think he was a competent physician because if he had been this would not have happened. After all he told her to "use her muscles" to hold up her prolased uterus.

> They (doctors in the E.D.) told me to see a gynecologist and I only knew one ..... but I was afraid of him. You got to feel confident in the person that you get.

Dorothy described a physician who told a friend that she had an inoperable malignant tumor and refused to operate. She decided to seek a second opinion and

discovered the tumor was a fibroid non-malignant tumor. The trauma associated with the error in diagnosis was seen as non-caring.

Competency also implies the ability to honestly inform the patient about outcomes of care and treatment. Nancy described an incident when she asked her physician if it would be painful when he removed some drains after her radical hysterectomy.

> He told me it wouldn't.... I wished he had been honest. The pain was so bad I couldn't stop shaking for days.

Physicians who do not medicate or prepare patients for a painful experience are seen as being non-caring and non-competent since they fail to understand or appreciate the personal pain associated with various procedures.

Patients also expect the nurse to be knowledgeable about their illness, medications, and medical care plan. If the nurse lacks this knowledge the patient will question the competency of the nurse. Rose described a nurse who failed to read her chart and almost gave her a medication when she was fasting for an xray which was scheduled in the morning. The

potential of harm, because the nurse lacked knowledge of the patient's medical care and history, is seen as a general disregard for his/her welfare.

Alice described an incident where the instructions given to her by the surgeon were completely different from what the nurse told her. She later questioned the doctor, who reinforced that she was using the spirometer correctly and that the nurse was wrong.

> How do you trust the nurse or believe she knows what to do? I'm left with the feeling that I have to question everything. It makes me feel uncomfortable.

Elie questioned the competency of the V.N.A. nurse who failed to assess his pulmonary edema, and the discharging physician for not prescribing the proper medication.

> I ended up in the ICU (at the community hospital) and was there for the next 24 hours. It is there they discovered the medication was not regulating the cardiac rhythm. The doctors there gave me a different medication to control my heart.

Non-Caring as Not Listening to What I'M Saying

The NON-CARING AS NOT LISTENING TO WHAT I'M SAYING metaphor portrays a care provider who is either not listening to the patient or is misunderstanding the

covert messages of the patient. In this study non-caring experiences associated with not hearing what the patient was saying involved patient- physician encounter rather than patient nurse interactions. Patients (38% , 6) described the inability of their doctors to hear the meaning in their communication.

An example of this is seen when Thomas described how anxious he felt during the insertion of a double lumen catheter;

> I feel claustrophobic to begin with, (patient was buried under sterile towels) ...anxious for them to get it (catheter) over with. I told them ...put me under. The surgeon replied, 'no way... it's too minor'.

In the above incident the physician failed to respond to the panic in Thomas's voice or to provide him with sedation, comfort or reassurance. The administration of a mild sedative may have conveyed acceptance and understanding of his anxiety and relieved the pain associated with the procedure.

Sam also had a great deal of difficulty communicating his needs to physicians. His fears of paralysis and death were expressed through his outbursts of hostility and rage which were directed at physicians who failed to explain what they were doing,

or to obtain his consent prior to treatments or diagnostic tests.

> When I questioned the need for an angiogram some of the doctors were annoyed I dared to question their orders..... It´s my body. I want to know what is going on.

Failure to answer the patient´s questions in a language that is understandable to the patient is seen as non-caring. Physicians frequently communicate complex information in a language that is not easily understood by the general public. This is particularly distressing to patients who need to have a sense of control and understanding of what is happening to their body, and tend to interpret this lack of clear communication as being non-caring.

Non-Caring as Shame and Humiliation

The non-caring as SHAME AND HUMILIATION metaphor portrays patients who felt "put down" by a care provider, or who were treated with disrespect, or were made to feel shameful about their illness or condition. Both male and female patients (31 % , 5) experienced feelings of shame and humiliation.

In one case a female patient experienced sexual harrassment from a dietary aide. This left Betty with a

sense of shame and a doubt about her own behavior. "How could it have happened?" How could she have prevented this behavior?

Similar to the metaphor of abandonment, patients experience a sense of rage and anger whenever they recall an experience which was humiliating. There is a general feeling of being personally attacked, and a sense of anger and rage directed at the nurse or physician who precipitated these feelings. This describes how Nancy felt when she was thrown out of her gynecologist´s office because she naively wore a tampon to control the bleeding after her cone biopsy.

Physicians who blame the patient for an inability to perform procedures is another example of how patients can experience a sense of shame and humiliation. This is what happened to Thomas:

> He (surgeon) took it out (catheter) and started to sputter about my anatomy ..... there was something wrong with my anatomy. He said I never saw a man as dry as this one.

Thomas was made to feel shame and humiliation that there was something radically wrong with his body. The experience of being ill makes a patient feel a sense of shame. Comments made to the patient, such as the above,

only make the patient feel more personal shame and anger toward the resident or person who inflicted the shame or humiliation.

Peter felt shame and humiliation when he fell off his motorcycle and injured his foot. It wasn't supposed to happen to him because he was extremely cautious and always wore protective pads. Biking is a sport that is a very important part of Peter's life. No matter what happens to him, he has no intention of giving up this sport.

> He (doctor) tells me I have to get another sport, that biking is too dangerous....And he said, don't come and see me if it happens again.

Peter felt put down by the doctor not only because of what he said, but the manner in which he spoke to him. He felt the doctor was degrading not only the sport but anyone who enjoys this sport.

Hierarchy of Patient Care Needs

In analyzing the patient's perception of the physician and the nurse, a hierarchy seemed to emerge which suggested an ordering or ranking of patient care needs. Patients tended to have a different set of needs

for medical and nursing care and some of these needs had to be met before a care-giver was perceived as caring.

Hierarchy of Nursing Care Needs

Patients (78%, 11) described the caring nurse as the one who provided frequent surveillance and assisted them with their physical needs for ambulation, toileting, and relief of pain and discomfort. Patients highly valued the nurses' ability to function as a health teacher and interpreter of the medical care plan. Data also suggest that if nurses were unable to meet the basic need for protection, physical comfort, emotional support, and health teaching the patient perceived the nurse to be non-caring regardless of her technical skills and knowledge.

The importance of frequent surveillance may not be fully appreciated by medical-surgical nurses or the hospital administration. Surveillance is an integral part of nursing practice within critical care nursing, and intensive care units are physically designed to facilitate the nurses' constant observation of the patient. The staffing levels are also higher in the intensive care units which further validates the

organization's support of this function. These same conditions do not exist on a medical surgical unit.

The medical-surgical nurse may not provide or perceive that patients desire frequent surveillance, particularly if they have been transferred from the intensive care unit, since it is no longer a medical necessity to provide close observation. This phenomenon was not seen on all patient care units, as surveillance appeared to be an integral part of the nursing function of the oncology units. On these units the same organizational barriers existed, namely lower staffing levels and the same physical design. Nevertheless, nurses on these units routinely visited the patient and asked if the patient needed any assistance. This practice created a sense of security and protection for the patient. Patients on these units described feeling as if the nurse, although invisible to the patient, would somehow always be there and able to protect them. These nurses created through their practice a similar experience to what the patient experienced in the intensive care units. Dorothy and Edward questioned if the oncology nurses were "different", or if they were "trained" differently. This comment was also expressed by Sam and Betty about the orthopedic nurses.

Illness/trauma and hospitalization cause patients to regress to an earlier stage of dependency. Each patient responded to this dependency differently based upon her/his personality type and coping mechanism. Some patients were fearful and ambivalent about being dependent, as was seen in the stories of Sean and Alice. Other patients coped with their dependency needs by trying to take control of the situation as was seen in the stories of Edward, Sam, Rose and Nancy.

Some patients are dependent upon the nurse for their basic activities of daily living; toileting, ambulating, feeding and personal comfort. Patients want to feel that they are not imposing upon the nurse, and that the nurse will be there when they need him/her. Data suggest that frequent surveillance tends to lower the patient´s anxiety level and may relieve his/her sense of "shame" about having the nurse care for his/her physical needs (Stories 3,4,6,7,8,14,15).

Another key nursing function is that of an interpreter of medical language, culture, mores and practices. Patients are reluctant to question the physician or admit that they did not understand a word of what he/she said. Patients fear they may be rejected or not held in high esteem by the physician if they

admit their ignorance. The nurse does not pose this same threat and may reflect the different status which the culture places upon the role of the physician and the nurse. It may be more acceptable to confide in the nurse their lack of understanding. It also means, however, that the nurse must have knowledge of not only the diagnosis, but the medical care plan and the rationale for such a plan of care (Stories 1,3,5,9,10,11,12,14,16).

Patients highly value the role of the nurse as a patient teacher. Nurses are expected to teach the patient the action and purpose of medications, prepare the patient for diagnostic tests, teach the patient health prevention and rehabilitation. The interpreter role falls into the category of patient teaching (Stories 1, 2, 6, 7, 11, 12, 13, 19).

Technical competency is an ingredient of caring which is highly valued by the patient. Patients however, are not able to evaluate the competency of the care provider. It is assumed that they are knowledgeable about the patient´s care. Nurses who are not knowledgeable about the patient´s diagnosis or medical management are defined as non-caring, and are seen as posing a threat to the safety of the patient.

Rose describes how fearful she felt when the nurse had not read the medical record and offered her medication when she was fasting. Similar fears were expressed by Alice when she perceived the nurse was unfamiliar with the use of the spirometer.

Emotional support, although highly valued by both gender, can only be effective if the other components of caring are present. If the patient feels the nurse did not protect the safety of the patient, and/or attend to her/his physical needs of care in a timely fashion, it appears that the technical skills and emotional support aren't sufficient in themselves to warrant the nurse being conceived as being caring. (Stories 3, 12, 13, 15).

Hierarchy of Medical Care

The patient's evaluation of the physician's caring abilities may reflect the patient's perception of the physician's responsibilities. Patients saw the curing/healing ability of the physician as his/her primary responsibility. Patients accepted the fact that the physician does not have all the answers, and are aware that it is a complex process to formulate a diagnosis and prescribe care. Therefore, the use of other clinical experts in the patient's care and is

seen as an example of caring. Inherent in this definition of caring is the requirement that the physician has higher level of knowledge, is analytical and has the ability to integrate and analyze data.

The physician is seen as a technical expert. Patients were frequently overwhelmed by the physicians ability to use highly technical diagnostic tools and procedures, and expected the physician to understand their application in the management of patient care. Although the nurse also uses technology in the practice of his/her profession, the data suggest that patients in this study placed greater responsibility on the physician to monitor their technical aspects of care than the nurse. This may have been biased by the clinical reason for hospitalization since 94 % of the patient population were admitted for a surgical and/or oncology condition. It may also mean that patients do not fully understand the significant role which nurses play in monitoring the technical aspects of care.

Patients want to know about their medical management. Many patients expressed a desire to be a part of the planning process and felt resentment if they were relegated to a passive role. Sam stated;

> I need to know what is going on with my body, after all, it's my body. I like to feel as if I have a say, and I'm informed prior to medical treatment or diagnostic tests are reaffirmed.

Therefore, patient education is an important component of caring for both the nurse and the physician.

Data suggest that patients preferred a physician who provided emotional support, yet this did not appear to be an essential part of the caring process. Physicians who are technically competent, able to relieve pain, and discomfort, and lack skill in providing emotional support are still defined as being caring. However, the majority of physicians in this study were surgeons, therefore, it is not clear if patients would describe primary care physicians, pediatricians or psychiatrist as caring if they lack a "bedside manner". Patients may place different expectations on surgeons than other physicians, or it may be that western cultures are more accepting of males who lack interpersonal skills. In either case, more research is needed to explore this phenomenon.

Patients' Comparison of Hospitalized Experiences

Ten patients in this study who had been hospitalized in a community hospital compared their experiences of caring and non-caring in each of these

settings. Characteristics which patients noted as being unique to a teaching hospital were;

1. Nature and frequency of teaching rounds
2. Primary Nursing
3. Knowledge and competency of the staff
4. Technology
5. House Staff rather than private doctors manage the medical care
6. Size and complexity of cases
7. Medical team of experts.

Patients had quite different experiences with teaching rounds. This was influenced by the clinical service to which the patient was assigned, and reflected the difference in manner or style of the various clinical services. For example, surgical rounds were less frequent than medical rounds, and orthopedic rounds consisted of one or two residents. The gynecologic residents presented individual cases outside the patient's room, and only discussed the daily treatment plan in the patient's presence.

Some patients found the teaching rounds to be intrusive while other patients felt they were active participants in the process. This may again reflect the style of the clinical service and the teacher. Patients

who were able to offer information or received information through this process found the rounds were helpful. Rounds which focused only on the learning needs of the students and did not convey a concern about the individual patient were seen as intrusive by both male and female patients.

The size, complexity and expertise of the medical and nursing staff in the teaching hospital were noted to be better than the community hospital, by most patients. Patients receive more diagnostic tests and are followed by a larger variety of medical experts in the teaching hospital. Perhaps Sam´s comment best summarizes the patient´s experience with and comparison of a teaching hospital:

> There is a definite difference... its size, scope, people, attitude, equipment. It´s the difference between a PT boat and a battleship.

Community hospitals are seen by many patients as being small and better able to personalize care. This view was not consistently shared with all patients and seems to reflect the personal satisfaction the patient had with nursing care. If the patient´s experience with the nursing care was not satisfactory, as was noted by Alice and Elie, he/she tended to feel the nursing care

at the community hospital was more personalized and therefore more caring.

Changes Noted in Caring Over the Past Years

Only female patients expressed concern about the recent changes in insurance coverage that limits the length of stay of a patient in a hospital. Rose voiced dissatisfaction with these changes and described vividly the impact on her and her family with her being discharged before the "bag" (colostomy) was ready. She disliked having her daughter see her in this condition and that her daughter would be required to personally clean her at home.

Elie's wife was frightened when her husband was rushed to a community hospital in Pulmonary Edema. They had a similar experience a year ago when this 84 year old man developed a reaction to his medication after he was discharged from having Open Heart surgery. It is frightening to experience a complication at home and for the care giving family member not to know what to do about it. In both of these cases Rose and Elie had to be readmitted.

Male patients did not express concern about being discharged earlier. However, male patients had either a

spouse, parent, or home aide available to provide physical care for them in the home. Women did not feel comfortable going home when they couldn't personally take care of their physical needs. This may reflect the female's expectation that she must be self sufficient in the home.

Summary of Findings

The study supports the findings of Watson (1983), and Lenininger (1978) that patients perceive that care providers who are able to convey a feeling of being special or having received an "extra effort" are caring.

This research supports the notion that patient's perceptions of caring and non-caring experiences is influenced by the patient's gender, age, education and social-cultural background. There was not an adequate sampling of minority persons within the study, therefore, findings are biased toward the white middle class patient's perceptions of what constitutes caring and non-caring experiences.

The data does suggest that males and females preferred care providers who were competent in both technical skills and communication skills. Both male

and female patients tended to place a higher significance on the physician role in monitoring the technical aspects of care than the nurse´s technical role. Patients also accepted physicians who exhibited "poor bedside manners" as long as they were able to "put them back together again". Nurses were judged to be caring if they were able to meet the physical needs of the patient, relieved pain and provided surveillance. However since the sample population was biased toward surgical and oncology patients (96 %), it may have influenced the findings in this study.

Female patients placed greater emphasis upon relationships between the care provider and patient. However, both sexes experienced an intense sense of gratification if a caring relationship was established between a care provider and the patient in much the same way a person experiences a loving relationship. This same degree of emotional intensity found in a "loving relationsip" was also found in patients who experienced humiliation from a care provider. In this contrasting experience, the feelings expressed by patients were intense anger and rage.

All patients experienced ideations about loss, death and dying. Patients´ coping mechanisms were

influenced by their gender, age, sex and social-cultural background. Many patients tended to repress these fears unless they had a care provider who was skillful in encouraging the expression of these emotions. Many care providers were either unable to assess these feelings and/or lacked the skill to support the patient. Female patients tended to verbalize these feeling more freely and sought the comfort of either the nurse, or their spouse.

Finally, data suggest that patients' perception of their caring needs may be different in terms of what they expect from physicians and nurses. Although it was not within the scope of the study to determine if the patient placed caring into a hierarchy, data suggest that patients' caring needs may be hierarchal, or patients may have pre-conditional needs that must be met before the patient perceives the care provider as being caring. Further research is needed to confirm these findings.

CHAPTER 6

SUMMARY, IMPLICATIONS AND CONCLUSIONS

Introduction

The purpose of this study was to explore the phenomenon of caring and non-caring from the hospitalized patient's perspective. Two primary research questions were asked: 1) What are the experiences that hospital patients perceive to be a demonstration of caring? and 2) What are the experiences that hospital patients perceive to be a demonstration of non-caring? Three secondary research questions were also asked: 1) Do female and male patients perceive demonstrations of caring and non-caring similarly, or are there gender differences?; 2) Is severity of illness a significant variable in how patients perceive a difference in demonstrations of caring and non-caring? Do patients perceive a difference in demonstrations of caring and non-caring from what they experienced five or more years ago?

An interpretive paradigm of research and analysis was used as the research approach. Indepth interviews served as the mode of data collection. Sixteen patients (eight female and eight male) were interviewed in the hospital and after their discharge, with the exception of two male patients. One of the latter patients died

while in the hospital and the other patient refused to participate in the post interview.

The research findings were presented by describing each patient's story of his/her experience in the hospital. Direct quotes were taken from the transcript and no attempt was made to correct grammar or sentence structure. Each patient described what s(he) perceived caring and non-caring experiences were, and discussed his/her feelings about these experiences. Patients also described their relationships with their physicians and nurses, and identified behavior which they perceived as caring and non-caring. Patients who had been hospitalized in community hospitals compared their experiences with those in a teaching hospital. Patients who were hospitalized five or more years ago described changes in hospitalized care and its impact on their caring perceptions.

Metaphors were used to analyze the caring and non-caring experiences of patients. A gender analysis of differences and similarities between male and female patients' interpretation of caring and non-caring experiences were presented in Chapter 5.

A hierarchy of patient care needs appeared to emerge from the data suggesting the possibility of different expectations and ranking of care needs for medical and nursing care.

The research sample was biased toward patients who were severely ill, therefore, the researcher was unable to analyze the significance, if any, which the severity of illness played upon the patient´s perception of caring and non-caring experiences. Six patients in this study have died since the research began ten months ago, and the prognosis of several other patients is poor.

Patients described changes they noticed in their caring and non-caring experiences in hospitals during the past five or more years. However, these same patients were hospitalized in a community hospitals rather than a medical center, so comparisons of changing health care practices and its affect upon caring needs may have been influenced by this variable. Patients described the difference noted in the community hospital and the teaching hospital, and gave their assessment of differences which they felt made one more caring than the other.

Major Findings

What Are the Experiences That Hospital Patients Perceive to Be a Demonstration of Caring?

Six major findings were found in this study that provide some understanding of the patient's caring needs within the complex world of hospitals. Each deals with the humanism which patients struggle to protect in a world that is strange and frightening to them.

1. All patients expressed some thoughts and ideations about loss, death and dying. Patients were fearful and apprehensive about what their illness would do to them and what would happen to them during and after their hospitalization. Common questions asked are: Will I survive ? Will my life be different? What is my prognosis?

2. Patients (81%) perceived that physicians and nurses who were able to convey a genuine concern for their welfare were caring. These same patients felt that they were more important to the care provider than the tasks to be performed, the technology to be monitored, or the learning need of the student. Patients want and need to feel that they are more than the "heart in 308", or a mannequin for students to

practice their skills. They are instead a "person" with fears, family problems and needs.

3. Seventy-five per cent of the patients described a caring person as someone who "goes out of his/her way" to make their hospitalization more comfortable and more personable. Physicians and nurses who break the rules and regulations or are assertive in demanding that the patient´s care take priority over other patients are perceived as being caring. This behavior is interpreted by the patient that the care provider thinks that the patient is "special".

4. Data suggested that different traits of importance were ascribed to various components of caring for physicians and nurses. Patients tended to evaluate caring differently for nurses than they did for physicians. Nurses were evaluated on their ability to protect the patient and meet their physical care needs in a timely manner. Nursing is seen within the broader cultural values as a female and "soft" profession, whereas, medicine is seen as a masculine profession and based upon " hard" scientific facts. How much this influenced the patient´s expectation of nursing care and medical care was not within the scope of this study.

Data further suggests that if nurses were unable to meet the the basic need for protection, physical comfort, emotional support, and health teaching, the patient perceived the nurse to be non-caring regardless of his/her technical skills.

5. Physicians who are technically competent, and able to relieve pain, and discomfort, but lack the ability or willingness to provide emotional support are still defined as being caring. This may be attributed to the fact that the majority of physicians in this study were male surgeons, and/or it may be more acceptable within western cultures for males and surgeons to lack interpersonal skills as long as they are technical competent.

6. In each case where the care provider humanized the approach to his/her practice, s(he) was seen as an expert practitioner in his/her own discipline. Expert care providers demonstrated the ability to go beyond the symptomatology and procedures to be performed. They were skillful in uncovering the covert needs of the patient. The expert clinician demonstrated an understanding of the emotional impact of the patient's illness and hospitalization, and the influence which

the patient's family and social- cultural background had upon the patient's recovery.

What Are the Experiences That Hospital Patients Perceive to Be a Demonstration of Non-Caring?

1. Patients describe non-caring as abandonment, shame and humiliation, not listening to their concerns, and failure to competently care and protect the patient from harm. These four metaphors are shown in Figure 4.

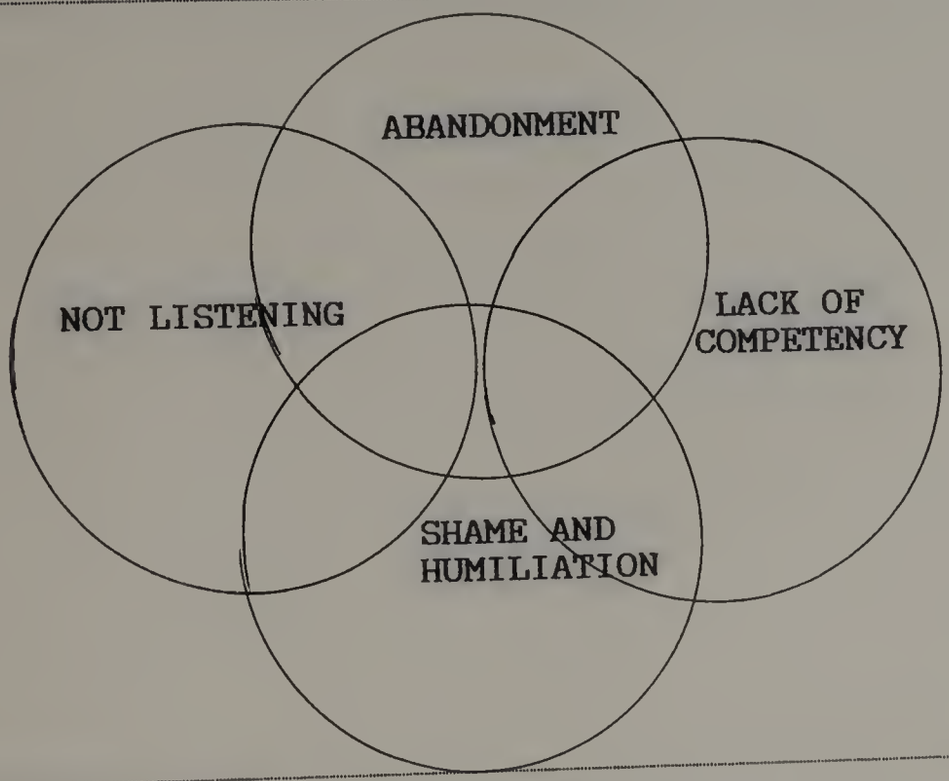

Figure 4 : Non-Caring Metaphors

The metaphors frequently are seen as interplays among each other, one frequently contributing to another non-caring event. For example, a patient who

has experienced abandonment may also experience shame and humiliation. A provider who fails to understand the true meaning of the patient´s verbal and nonverbal communication may also be seen by some patients as being incompetent.

2. In 31% (5) of the patients, the resident and intern were seen as novices and uncaring. Patients described the uncaring novice as one who was preoccupied with his/her own learning needs at the expense of the patient´s needs.

However, if the clinical instructor showed compassion and understanding of the patient, the patients appeared to be more accepting of the intern and resident. For example, Dorothy, a retired school teacher described the skillfulness of Dr. P. as he carefully and compassionately assisted the students to understand her history and symptomatology. In this case, the patient felt protected, and the students observed how an expert practitioner integrated knowledge and caring into practice. He skillfully included the patient into the teaching process, and gained more information about the patient´s symptomatology and response to therapy.

Do Female and Male Patients Perceive Demonstrations of Caring and Non-Caring Similarly, or Are There Gender Differences?

This study supports the notion that male and female patients have similar perspectives regarding caring and non-caring experiences, but each gender places a different degree of importance on various aspects of caring and non-caring experiences. Gender differences were also influenced by the patient's age, education and social-cultural background. Specific differences are noted below:

1. Older female patients tended to play the passive patient role, while younger educated females were assertive and demanding of what they perceived as their patient rights.

2. Male patients in this study were more comfortable expressing anger than female patients. Females patients who expressed anger tended to rationalize and justify their behavior and feelings and questioned what they had done to justify rejection or abandonment. Male patients did not internalize their feeling of anger, but attributed the abandonment or rejection as an individual trait of the care provider and not as a personal weakness in themselves.

3. Female patients tended to place a higher value on their relationship with the physician and nurse. Several female patients identified nurses as being uncaring if they had not established a relationship with the nurse. This was not true for male patients. In one instance a female patient even commented on her acceptance of her physician´s failure to monitor her steroid level even though it caused a degeneration of her bones, because the physician was "caring and concerned" about the welfare of her unborn child.

4. Both genders placed a higher degree of emphasis on the physician´s technical competency. Physicians were seen competent if they could cure, heal, or improve the quality of the patient´s life. Both genders tended to be more tolerant of physicians who lacked a "bedside manner".

5. Although male patients did not identify the establishment of a relationship as an an essential ingredient of caring, male patients who did experience a relationship with either a nurse or a physician expressed a greater degree of satisfaction with their care and an intense feeling of love and affection

toward the care provider. This suggests that relationship may be more important to the male patient than reported.

Do Patients Perceive a Difference in Demonstrations of Caring and Non-Caring From What They Experienced Five or More Years Ago?

Patients expressed a recognition that health care is more complex than it was years ago. This was especially prevalent in the academic center used for this study since it places great emphasis upon its accomplishments in research, teaching and use of technology. In spite of the complexity of the teaching hospital used in this study, patients felt they were properly prepared for diagnostic tests, and that doctors, nurses and technicians created a caring environment.

Patients hospitalized five or more years ago were previously hospitalized in community hospitals, therefore, comparisons about the changes in health care tended to be a comparison of differences in teaching and community hospitals. Patients noted the major differences in teaching hospitals was its complexity of procedures, diagnostic tools, technology, greater

concentration on teaching, and the use of teams of expert physicians rather than one physician who managed the care.

Several patients commented that the availability of the nurses was better in the community hospital and, therefore, described the nurses in the community hospital as being more caring. Nurses in the teaching hospital were seen as being competent and more knowledgeable about the patient´s care than community hospital nurses. Patients also expressed greater satisfaction with the use of primary nursing which is used in the study site, than team nursing which is used in most community hospitals.

Several female patients expressed dissatisfaction with the recent emphasis placed on insurance companies and medicare to shorten the coverage of various medical illnesses. Thirty-eight % of the females patients and the spouse of a male patient expressed concern and apprehension about being required to assume personal responsibility for their (or husband´s) post discharge care. Two patients (one male and one female) developed complications at home which required re-admission.

Research Findings in Relation to the Literature

Several variables influencing the perception of caring which were reported in the Literature Review (Chapter Three) were found in this study. Major areas of similarity are:

1. Watson (1983) and Leininger's (1978) notion that social-cultural background influences the patient's role in the hospital and his/her interpretation of caring was seen in all cases.

2. Gender differences noted by the Weiss (1984) study on caring were also supported by this research. Specific findings on gender differences and similarities may be found in Chapter 5. There isn't sufficient data to support the notion that female patients are accepting of care providers who are not as competent even though one patient was accepting of her physician lack of monitoring of drug levels. Several female patients expressed concern about the competency of either their doctor or nurse. However, as stated earlier, most patients accepted physicians who had poor bedside manners as long as the physician was perceived as technically competent.

Findings also suggest that there are differences within the genders depending upon the patient's age, education and socialization. Although male patients neither expected nor expressed a desire for a relationship with the care provider, male patients expressed greater satisfaction with the level of care if a relationship did exist between the patient and a care provider (Stories 6,8,9).

In addition to findings reported in the literature, the findings in this study suggest that patients may use sexual stereotyping in describing their expectations of physicians and nurses. Patients may have ascribed the more common masculine traits of being analytical, logical, rational and having leadership traits to the physician. The feminine traits of being empathetic, emotional, supportive, communicative and desiring affiliation appeared to be ascribed to the nurse. Whether the patient attributes these characteristic to the functions of the nurse or doctor, or whether it was influenced by the gender of the care provider was not addressed by this research. Additional research is needed to determine whether patients ascribed different caring traits to female doctors or male nurses.

3. This research also supports the findings of Gardner and Wheeler (1981) that nurses who perform supportive and nurturing behavior are seen as more caring. Both male and female patients saw the nurse as supportive if their physical care was administered adequately and on time, and if the nurse conveyed an attitude of concern.

Gardner and Wheeler´s (1981) notion that nurses are supportive when they help patients feel confident that adequate medical care was provided, is also seen when patients saw nurses as supportive when they functioned as a medical interpreter.

4. The research also supports the notion of DiMatteo and DiNichola (1982) that the physician´s ability to cure, treat, or "put back together " is perceived as an example of caring. These findings also support the notion that medicine is perceived to be a highly technical profession that requires a high level of knowledge and competency.

5. Leininger (1978) and Watson (1983) suggest that American and non-western patients may have similar expectations for nursing care, and may place different emphasis upon caring than American nurses. This study

supports this notion and found that patients appeared to place greater emphasis upon their need for protection, surveillance and physical care than nurses. Many nurses in this study appeared to place greater emphasis on the tasks to be performed, maintenance of technology, administration of medication and psychological support of the patient. Although these are important to the patient, they are not as important as surveillance and physical care.

6. Lazare's (1987) hypothesis that illness causes patients to experience a sense of shame was also found in this study. Dorothy described feeling like a "freak", and Peter described feeling shame because he injured his foot in a motorcycle accident. This was "not suppose to happen to him". Similar feelings of shame were also seen in Edward's story as he carefully uses the word "infection" to describe his malignancy (Stories 4,7,10).

In summary, the research findings in this study reaffirm the notion that variables influence the patient's perception of caring and non-caring. The literature, however, does not address the patient's perception of caring and non-caring, nor does it describe the caring and non-caring behavior of

physicians or nurses. Although the literature has described some gender differences between male and female descriptions of caring, the existing literature has not synthesized the gender differences and similarities into the descriptions of caring and non-caring behavior of physicians or nurses.

This study makes an attempt to understand and explore the patient's conception of caring and non-caring by defining various metaphors that describe the caring and non-caring nurse and physician. Such an effort provides a new way of understanding the phenomenon of caring/non-caring from the patient's vantage point and opens new avenues for further development of research.

Implications for Practice and Education

The results of this research indicate that the patient has his/her own definition of caring and non-caring which is some respects may be different from both the care providers and other patients. Most providers would agree with the patient's basic values that the underlying principles of caring are human-centeredness and personalized care. How this is translated into practice, however, may be different for the care provider and the patient.

1. Since patients place a great deal of value on their nursing needs for protection, surveillance, physical care and health teaching, nurses might consider placing more emphasis on these needs.

2. Physicians might contribute to patient satisfaction by communicating medical information in a language that is easily understood by the general public, and develop listening and interviewing skills that will facilitate patient communication and education. Therefore, medical curriculum might consider including physician patient encounters and interviewing skills which focuses upon how to obtain and use the patient's perspective of their illness and care in data collection. Included in such a course might be the physicians role in patient teaching and skills in how to teach a patient.

3. The findings in this study suggest that ideations about death and dying may not be unique to cancer patients and may be a more common phenomenon than the literature has reported. Further research is needed to validate these findings. Regardless, illness is a loss, a loss of function, self-esteem and independence. Thus, patients tend to go through the various stages of grieving, anger, depression and

re-assessment of their life style. Physicians and nurses may have underestimated the patient's fear of hospitalization, especially in patients for whom the care providers do not anticipate that death will occur.

Patient's ideation about death may have also been influenced by the severity of illness of the sample population. Regardless of the cause, care providers might do well by being aware of this phenomenon, assess the patient's response toward their illness and create opportunities for patients to express these concerns.

Nursing and medical education might also include a course on death and dying. Such a course should not focus only on patients who are dying, but should incorporate an understanding of the emotional trauma which illness and hospitalization have on patients.

4. Patients who expressed a need for frequent surveillance may be responding to their unresolved fears about death and dying, and their lack of understanding about medical and nursing practices. Patients expressed greater comfort on the oncology and orthopedic units where it was common practice for the nurses to visit patients frequently, and to ask if the

patient needed assistance. In the latter case, the patient felt as if the nurse was always available.

Frequent surveillance was not a common experience for patients on the surgical units. Patients were required to ring for the nurse and wait for assistance. Patients described nurses who were not as readily available or who failed to answer lights quickly as non-caring.

5. This study underscores the importance which the clinical teacher plays in the learning process. In incidents where the clinician teacher modeled caring and compassion, and allowed the patient to participate in the teaching rounds, the patient felt a part of the process. Data also suggest that the clinical expert was able to demonstrate a student-centered approach to teaching and modeled a patient-centered approach to students.

6. Curriculum for both nursing and medical education might be developed around the underpinnings of a holistic approach to patient care. Nursing and medical students, interns and residents need assistance in integrating knowledge of the pathophsiology, technology, and differential diagnosis with the social

and psycological aspects of illness and hospitalization. Included in this approach could also be concepts on the phenomenon of caring and non-caring, and the patient´s perceptions of this phenomenon.

Implications for Administration

Hospital administration might do well by understanding the patient´s perspectives and expectations about care. Other businesses and organizations have understood the importance of obtaining the consumer´s perspectives in marketing and evaluating the effectiveness of the organization. The hospital industry has been slow in utilizing this approach. Creating a caring environment would produce a patient-centered environment.

1. Several different strategies can be used to assess the hospitalized patient´s needs, such as, patient focus groups, interviews, and questionnaires.

2. If organizations do elect to become more consumer or patient orientated, they may need to communicate these changing values and expectations to their employees. Communication of organizational values can be done through employee orientation. Training sessions can be established on the caring needs of

patients, interview skills and patient education. Clarification of management expectations and accountability need to be delineated along with clarification of each persons responsibility in the creation a patient centered environment.

3. Focus groups with medical and nurses staff, and students can be used to assess the current working environment. Patient data should be shared with staff and students. Strategies to make the environment more caring might be more effective with involvement of staff members and students in the analysis of the processes that impact patient care as well as the design of the program.

Implications for Future Research

Although this study proposes common elements of the patients perception of caring and non-caring, it also raises many other questions that might benefit from further research. Recommendation for further research questions are:

1. Do all hospital patients experience ideations about loss, death and dying?
2. Do patient expectations of male nurses differ from female nurses?

3. Do patient expectations of female physicians differ from male physicians?
4. Do male patients experience a higher level of satisfaction with caring if they have established a relationship with a care provider?
5. Do patients have a hierarchy of needs for nursing and medical care? If a hierarchy does exist, what order do patients rank their needs of care for medicical and nursing care?
6. Do patients describe medical physicians who lack a "bedside manner" as caring?
7. How do hospitalized minority patients describe caring and non-caring?

Conclusion

Findings in this study suggest that patients perceive caring from two primary spheres, curing and nurturing. The physician plays the critical role in the curing process while the nurse plays the key role as the nurturer. Patients see the physician as the "healer", and therefore the person who is knowledgeable about his/her illness and treatment. The physician is expected to be technically competent above all other things. The physician is also seen as the "leader" of the team, and the one who directs the other members of

the health care team. The characteristics of the physician are similar to those described by Gilligan (1988) and others as being masculine traits.

The nurse, on the other hand, is seen as the one who is there twenty four hours. He/she is expected to play the traditional female role as the supporter, nurturer and the one who carries out the medical care plan. Nancy articulates the difference between the two care providers:

> The physician´s is a much more technical job in my eyes. They come in, do their surgery, and just monitor your condition. They are not really caring in the sense that they´re not with you when you are throwing up or when you are in pain.... They march in and say , ´oh ya, give her some of this or that and then leave. They don´t give it. Oh, they are caring, but its a different type of caring.....The nurse is the one who really takes care of you.

These same thoughts were expressed by other patients. Peter stated:

> The caring part of it comes from the nurse. The doctors do just what they have to do. Caring comes after the thing is put back together, then the caring begins.

Figure 5 depicts the interconnection of the caring model and how the expert clinician actually creates an inner circle. Caring can be characterized by two

interconnecting circles; one circle that is technical and analytical, and the other circle as nurturing and supportive. In the stories presented in Chapter 4, examples were given of expert clinicans, both physicians and nurses, who had mastered both of these competencies.

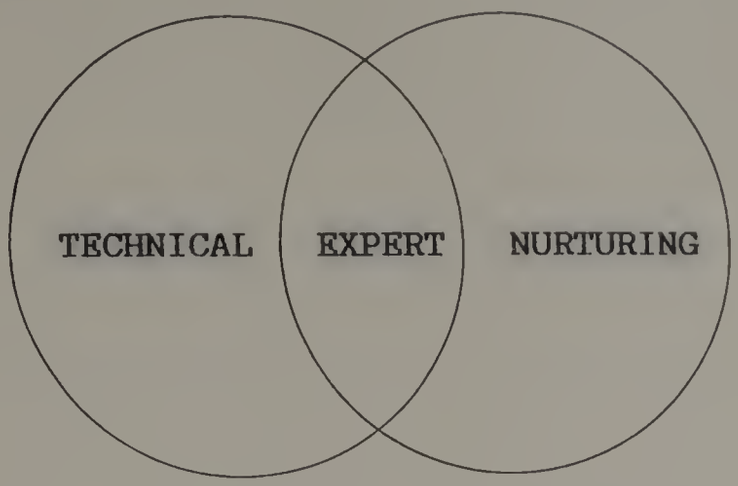

Figure 5 : Interconnection of the Caring Model

Nurses and physicians who are clinical experts in their respective disciplines fall within the overlapping part of the circle, since each has mastered the traditional male characteristics of being analytical, objective, and technical, while at the same time are nurturing, supportive, communicative and able to establish a relationship with the patient. Neither trait is superior to the other, however the combined traits of technical and nurturer are superior to either one.

The clinical experts seen in this study are a blend of the two caring characteristics and, therefore, a blend of the male (technical and analytical) and female (nuturer and educator), characteristics that make up the caring model. It is this researcher belief that the development of this clinical expert should be the goal for both medical and nursing education. Practitioners need to be proficient in the complex analysis and application of science and technology, as well as skillful in the art of medicine and nursing. It is the human-centeredness of caring and curing that the patient seeks to obtain in a hospital.

APPENDICES

APPENDIX A : INTERVIEW GUIDE

General questions about caring and non-caring:

1. Could you give me a little background information about yourself, such as your age, martial status, occupation, etc.? Is there anything else you'd like to tell me about you?

2. Could you tell me the ways in which you felt cared for during your hospitalization? Were there any experiences which you felt were non-caring, by that I mean you felt put down, or not treated like a human being? Is there anything else you'd like to share?

3. What brought you to the hospital? Describe how you felt when you were being admitted? Were there any feelings associated with this experience? Were their any negative feeling assocated with this experience? Is there anything else?

4. How would you describe the nurses, are they caring? What do they do to make you feel as they are caring? Have you experience a nurse(s) who were non-caring or made you feel you were not important, put down or not a human being? Please describe these experiences? How did you feel when a nurse exhibits behavior that is caring? How did you feel when a nurse exhibits behavior that is non-caring? Is there anything else you'd like to share?

5. How would you describe the physicians, house staff (interns and residents), are they caring? What is it that the physician does that makes you feel that he/she is caring? Have you experienced any physician who was non-caring, put you down, made you feel you were not important or not a human being? Could you describe these experiences and your feelings? Is there anything else you'd like to share?

6. Please describe your relationship with your physician; house staff; and nurses? Is this a satisfactory relationship? Would you like this relationship to be different? If so, in what way? Is there anything else?

Continued, next page.

APPENDIX A, continued.

7. When you think of a caring person, what characteristics or behavior would best describe this person?

8. What characteristics or behavior would describe a person who was not caring?

Specific questions about common experiences in a hospital:

9. All patients experience various diagnosis tests such as blood work, xrays, ekg, etc could you describe these experiences? Were their any negative experiences associated with these experience? Is there anything else you'ld like to share about these experience?

10. Teaching rounds are a common part of a university hospital. Could you describe what occurs and how you feel during these rounds? Did you experience any negative feeling during the rounds? Did you feel included or excluded from the physicians' conversation? Is there anything else you'd like to share about these rounds?

11. If you could change anything in the hospital, what would you change?

12. How could the hospital, physicians and nurses better meet your needs, and be more sensitive and caring?

APPENDIX B: DEMOGRAPHIC DATA OF SAMPLE POPULATION

PATIENT	AGE	SEX	RACE	OCCUPATION	MARITAL STATUS	EDUCATION	FAMILY SUPPORT	ADMISSION	SERVICE
Marie	29	F	Hispanic	Unemployed Housewife	Single Parent	H.S.	3 Children Welfare	Clinic	Oncology
Betty	37	F	Caucasian	Housewife	Married	LPN	1 child Husband	Elective	Orthopedics
Keith	22	M	Caucasian	Unemployed Laborer	Single	H.S.	Parents	Emergency	Trauma
Edward	70	M	Caucasian	Retired Ins. Exec.	Married	College	Wife and Adult Children	Clinic	Oncology
Marion	69	F	Caucasian	Retired Fact. Worker	Div. w/ 5 child.	H.S.	Mate companion Daughter w/child	Elective	GYN
Thomas	69	M	Caucasian	Retired Post Officer	Married	H.S.	Wife 3 step children	Emergency	Oncology
Dorothy	65	F	Caucasian	Retired School Teach.	Married	College	Husband 2 adult children	Clinic	Oncology
Sam	46	M	Caucasian	Uemployed Builder/Acct.	Divorced	Post H.S.	Alone/former wife 2 children	Emergency	Trauma
John	61	M	Caucasian	Retired Truck Driver	Married	H.S.	Wife/? 5 children Grandchild	Clinic	Medicine

continued next page

APPENDIX B, continued

PATIENT	AGE	SEX	RACE	OCCUPATION	MARITAL STATUS	EDUCATION	FAMILY SUPPORT	ADMISSION	SERVICE
Peter	31	M	Caucasian	Manager Auto Mechanic	Married	H.S.	Wife 3 Children	Emergency	Post-Trauma Orthopedics
Mary	54	F	Caucasian	Unemployed Fact. Work.	Twice Divorced	H.S.	Lives with son-14 Older Children	Elective	GYN Oncology
Nancy	26	F	Caucasian	Manager GTE	Single	College	Alone CT Boyfriend	Elective	GYN
Rose	60	F	Caucasian	Housewife	Married	H.S.	2 children	Emergency	Surgery
Sean	19	M	Caucasian	Unemployed Waiter	Single	H.S.	Alone/Girlfriend Parent	Emergency	Trauma Surgery
Alice	67	F	Caucasian	Retired Accountant	Married	College	Husband 2 Adult Children	Emergency	Surgery
Elie	84	M	Caucasian	Retired Teacher	Twice Married	College	Wife Adult Children	Elective	Cardiac Surgery

APPENDIX C: CONSENT FORM

DESCRIPTIVE STUDY CONCERNING THE PATIENT'S EXPERIENCE OF CARING AND NON-CARING

Dissertation research conducted by:

Gail Frieswick
86 George Hill Rd.
Grafton Massachusetts 01519
(508) 839-9806

CONSENT FORM

I am a former nurse and a graduate student at the University of Massachusetts. I am here to explain a research study that I would like to conduct with you while you are a patient at the Medical Center.

My professional experience as a nurse has given me an understanding of the complexity of patient care today. It has also given me an appreciation of the uniqueness which hospitalization can create for each patient and family. However, I have a hunch that the patient's perception of caring and non-caring may be different than a physician's or a nurse's. I am aware that it is easy for health professionals to become so caught up in the busyness of their own work, and the complexity of the care they provide, that they may not fully appreciate those aspects of caring that a patient values as important.

This study has been designed to identify caring and non-caring behaviors as seen by patients. In order to find this out, I am seeking permission to conduct a taped interview in which I will ask you to describe your perceptions of caring or non-caring experiences while you are a patient in the Medical Center. I would also like to interview you two to four weeks after you are discharged to see if your reflections on these experiences are the same or if they are altered. Therefore, I am seeking permission to interview you in your home two to four weeks after you are discharged.

As part of this study I am also seeking permission to review your medical record to identify how the various health professionals record the care they provide. This also helps me gain a better understanding of the uniqueness of your care and illness.

The information that I gain from this study will be keep confidential and will be written in a way that no individual may be identified. The exception to this rule would be a case where a patient's safety is at risk. In this case I would inform you that I need to tell your physician of safety issues that may affect your welfare.

The final report will be a public record at the University, and there may also be a scientific journal article describing this study. In order to maintain the confidentiality and uniqueness of your experiences, this study will be written in descriptive terms in which you will be given a different name to protect your identity.

There will be no personal risk or benefits to you. The information gained, however, may be of benefit to the medical and nursing profession by contributing to the understanding of caring as seen by patients.

YOUR PARTICIPATION IN THE PROJECT IS ENTIRELY VOLUNTARY. YOU MAY WITHDRAW FROM THE STUDY AT ANY TIME WITHOUT ANY PREJUDICE TO YOU OR THE SUBJECT MATTER.

I have already reviewed the proposed study with your physician and he/she has felt that in no way will this study interfere with your care or welfare.

Are there any questions?

Please feel free to ask any questions you may have about the study or about your research subject. If at any time during or after the study, you would like to discuss your experiences with someone, you may contact Jane Miner, at 856-4261. She is the Administrative Coordinator for the Committee on the Protection of Human Subjects in Research at the Medical Center.

The purpose and the procedures of this research project have been explained to me, and I understand them. I agree to participate as a subject in this research project and allow the researcher to review my medical records. I understand that I may end my participation at any time.

Thank you,
Gail Frieswick

Signature_____

Print name_____

Date_____ Researcher_____

APPENDIX D : CARING THEMES

MALE	FAMILY	PERSON	CURING	UNDERSTANDING	SPECIAL
3)		*	*		*
4)		*	*		*
6)	*	*	*	*	*
8)		*	*	*	*
9)	*	*	*		*
10)		*	*		
14)		*	*	*	
16)					
sub total	2	7	8	3	5
FEMALE					
1)		*	*	*	*
2)		*	*		*
5)	*	*	*		*
7)		*	*	*	*
11)	*		*		
12)		*	*	*	*
13)	*	*	*		*
15)			*		*
sub total	3	6	8	3	7
TOTAL	5	13	16	6	12

APPENDIX E : NON-CARING THEMES

MALE	LACK of LISTENING	ABANDONMENT	SHAME/HUMILIATION		LACK of COMPETENCY
3)		*	*		
4)			*		*
6)	*			*	
8)	*	*			*
9)		*			*
10)		*	*	*	*
14)		*	*		
16)	*	*			*
sub total	3	6	4	2	5

FEMALE					
1)	*				
2)		*		*	
5)					*
7)		*	*		*
11)		*			
12)	*	*		*	*
13)		*			*
15)	*	*		*	*
sub total	3	6	1	3	5

TOTAL	6	12	5	5	10

BIBLIOGRAPHY

Baron, R. (1985). An introduction to medical phenomenology: I can't hear you while I'm listening. Annals of Internal Medicine, 103, 606-611

Benner, P. and Wrubel, J. (1986). The primacy of caring: Stress and coping in health and illness. Menlo Park, California: Addison-Wesley Publishing Company.

Benson, J. Kenneth. (1977). Organizations: A dialectical view. Administrative Science Quarterly, 22, 1-19.

Berger, P. and Luchman, T. (1966). The social construction of reality. Garden City: Anchor Books.

Bevis, E.O. (1981). Caring: A life force. In M. Leininger (Ed.) Caring: An essential human need, Thorofare, N.J.: Charles B. Slack.

Blattner, B. (1985). Holistic nursing. Englewood Cliffs, N.J.: Prentice-Hall, Inc.

Blumer, H. (1969). Symbolic interactions: Perspective and method. Englewood Cliffs, New Jersey: Prentice-Hall, Inc.

Brenner, P., Boyd, C. and Thompson, T. et al. (1986). The care symposium: Consideration for nursing administrators. Journal of Nursing Administration, 16, 25-30.

Brown, L. (1986). The experience of care: Patient perspectives. Top Clinical Nurse, 8, 56-62.

Burrell, G. and Morgan, G. (1979). Sociological paradigms and organizational analysis. Portsmouth, N.H.: Heinemann.

Byerly, E. L. (1976). The nurse-researcher as participant observer setting. In Pamela J. Brink (Eds.), Transcultural nursing; A book of readings. Englewood Cliffs: Prestice-Hall.

Chremreick, B. and English, D. (1973). Midwives, witches and nurses: A history of women healers. Old Westbury, N.Y.: Feminist Press.

DiMatteo, M.R., and DiNicola, D.D. (1982). Achieving patient compliance: The psychology of the medical practitioner's role. New York: Pergamon Press.

Emerson, J.P. (1976). Behavior in private places: Sustaining definitions of reality in gynecological examinations. Recent Sociology, 2, 74-95.

Francis, V., Korsch, B.M. and Morris, M.J. (1969). Gaps in doctor-patient communication. New England Journal of Medicine, 280, 535-540.

Freemon, B., Negnete, V., Davis, M. and Korsch, B. (1971). Gaps in doctor-patient communication: Doctor-patient interaction analysis. Pediatric Research, 5, 298-311.

Freire, P. (1979). Pedagogey of the oppressed. New York: Comtiumim Publishing Company.

Gardner, K. (1981). Supportive Nursing: A critical review of literature. Journal of Psychiatric Nursing and Mental Health Services, 17, 6-10.

Gardner, K.G. and Wheeler, E. (1981). Patients and Staff Nurses Perceptions of Supportive Nursing Behavior: A preliminary analysis. In M. Leininger (Ed.) Caring: An essential human need. Thorofare, N.J.: Charles B. Slack.

Gaunt, D. (1984). A theoretical description of caring as action. In N. Leininger (Eds.), Care: The essence of nursing and health. Thorofare, N.J.: Charles B. Slack.

Gaylin, W. (1976). Caring. New York: Avon Books.

Germain, C.P.H. (1979). The cancer unit: An ethnography. Wakefield, MA: Nursing Resources, Inc.

Germain, C.P.H. (1986). Ethnography: The method. In P.L. Murhall and C.J. Oliver (Eds.), Nursing research: a qualitative perspective (pp. 147-162). Norwalk, CT: Appleton-Century-Croft.

Gilligan, C. (1977). In a different voice: Women's conception of self and morality. Harvard Educational Review, 47, 52-87.

Goffman, E. (1976). The nature of difference and demeanor. Interaction Ritual, New York: Anchor/Doubleday

Gray, E.D. (1981). Patriarchy as a conceptual trap. Gender and Society, 2, 1-19.

Hall, C.S. and Lindzey, F. (1978) Theories of personality. 3rd ed. New York: Wiley.

Heidegger, M. (1962). Being and Time. Translated by Macquanie and Robenson. New York: Harper and Row.

Husserl, E. (1977). Phenomenological psychology. The Hague: Martinus Nijhoff.

Jennings B. M. (1987). Social support: A way to a climate of caring. Nursing Administration Quarterly, 11, 63-71.

Kahana, R. and Bibring, G. (1964) Personality types in medical management. In Zinoerg NE, Psychiatry and medical practice in a general hospital. New York: University Press.

Kalisch, P.A. and Kalisch, B.J. (1982). Sex-role stereotyping of nurses and physicians on prime-time television: A dictatomy of occupational portrayals. Sex Roles, 10, 533-553.

Krieger, D. (1979). The therapeutic touch. Englewood Cliffs, New Jersey: Prentice-Hall, Inc.

Lazare, A. and Eisenthal, S. (1975). Clinician/Patient relation I: Attending to the patient's perspective. Arch. Gen. Psychiatry, 32, 553-558.

Lazare, A. and Eisenthal, S. (1979). A negotiated approach to the clinical encounter: Part I. Attending to the patient's perspective. In Lazare's (Eds.), Outpatient psychiatry: diagnosis and treatment. Baltimore, William and Wilkins.

Lazare, A. (1987). Shame and humiliation in medical encounter. Arch. Internal Medicine, 147, 1653-1658.

Leininger, M. M. (1978). Transcultural nursing: Concept, theories and practices. New York: Wiley.

Leininger, M. M. (1981). ed. Caring: An essential human need. Thorofare, New Jersey: Charles B. Slack.

Leininger, M. M. (1984). ed. Care:The essence of nursing and health. Thorofare, N.J.: Slack Incorporated.

Leininger, M. M. (1985). Qualitative research methods in nursing. Orlando: Grune and Stratton, Inc.

May, R. (1969). Law and will. New York: Norton.

Mayeroff, M. (1971). On Caring. New York: Harper and Row Publishers.

Merleau-Ponty, M. (1964). The primacy of perception. Evanston, Ill. Northwestern University Press.

Miller, J.B. (1976). Toward a new psychology of women. Boston: Beacon Press.

Miller, L. (1987). The human care perspective in nursing administration. Journal of Nursing Administration, 17, 10-12.

Morrison, A. P. (1983). Shame, the ideal self and narcissism. Contempt Psychoanalysis, 19, 295-318.

Nayak, M.I. and Nayak, O.T. (1984). Games that professionals play: The social psychology of physician-nurse interaction. Social Science Med, 18, 1063-1069.

Novack, D. (1987). Clinical review: Therapeutic aspects of the clinical encounter. Journal of General Internal Medicine, 2, 346-355.

Patterson, J. and Zderad, L. (1976). Humanistic Nursing: New York: John Wiley and Sons.

Pattison, E.M. (1977). The experience of dying. Englewood Cliffs, N.J.: Prentice-Hall, Inc.

Patton, M. Q. (1980). Qualitative evaluation methods. Beverly Hills: Sage Publication.

Quill, T.E. (1983). Partnership in patient care: A contractual approach. Annals of Internal Medicine, 98, 228-234.

Quill, T.E. (1989). Recognizing and adjusting to barriers in doctor-patient communication. Annals of Internal Medicine, 111, p. 51-57.

Ray, M. (1984). The development of a classification system of institutional caring. In M. Leininger (Eds.), Care: The essence of nursing and health. Thorofare, N. J.: Charles B. Slack.

Ray, M. (1985). A philosophical method to study nursing phenomenon. In M. Leininger (Eds.), Qualitative research method in nursing. New York: Grune and Stratton.

Ray, M. (1989). The theory of bureaucratic caring for nursing practice in the organizational culture. Nursing Administration Quarterly, 13, 31-42.

Rindler, M. (1984). Back to patients: Process vs. outcome for hospital managers. Hospital and Health Services Adm., 12, 15-22.

Roberts, S. (1983). Oppressed group behavior: Implication for nursing. ANS, 5, 21-30.

Swanson-Kauffman, K. (1986). Caring the instance of unexpected early pregnancy. Clinical Nurse 16, 107-110.

Taylor, S. J. and Bogdan R. (1984). Introduction to qualitative research methods: The search for meanings. 2nd. ed. New York: John Wiley and Sons.

Twaddle A., and Hessler, M. (1977). A sociology of health. St. Louis: C.O. Mosky Co.

Waterman, A.S. (1981) Individualism and interdependence. American Psychologist, 36, 762-773.

Watson, J. (1983). Caring & loss-grieving experiences, new knowledge for nursing practice. Research presented at the American Nurses' Association's Clinical and Scientific Sessions, Denver, Colorado.

Watson J. (1983). Nursing: Human science and human care. Norwalk, Ct: Appleton-Century Croft.

Weick, K. (1979). Enactment and organizing. The social psychology of organizing. 2nd. ed. New York: McGraw Hill.

Weiss, B. (1984). Gender-Related perceptions of caring in the nurse-patient relationship. In. M. Leininger (eds.), Care: the essence of nursing and health. Thorofare, New Jersey: Charles B. Slack.

West, C. and Zimmerman, D.H. (1987). Doing gender. Gender and Society, 1, 125-151.