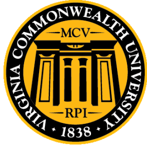

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AN EXPLORATORY STUDY

TO DETERMINE THE EMOTIONAL NEEDS

OF TERMINALLY ILL PATIENTS

by

June Hudnall Turnage

B.S.N., Medical College of Virginia, 1959

Thesis

submitted in partial fulfillment of the requirements for the

Degree of Master of Science

School of Graduate Studies

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Richmond, Virginia

June, 1971

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This thesis by June Hudnall Turnage is accepted in its present form as satisfying the thesis requirement for the degree of Master of Science.

Date: Approved:

4.29.71

Advisor, Chairman of Graduate Committee

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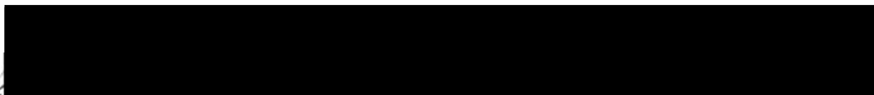
APPROVED:

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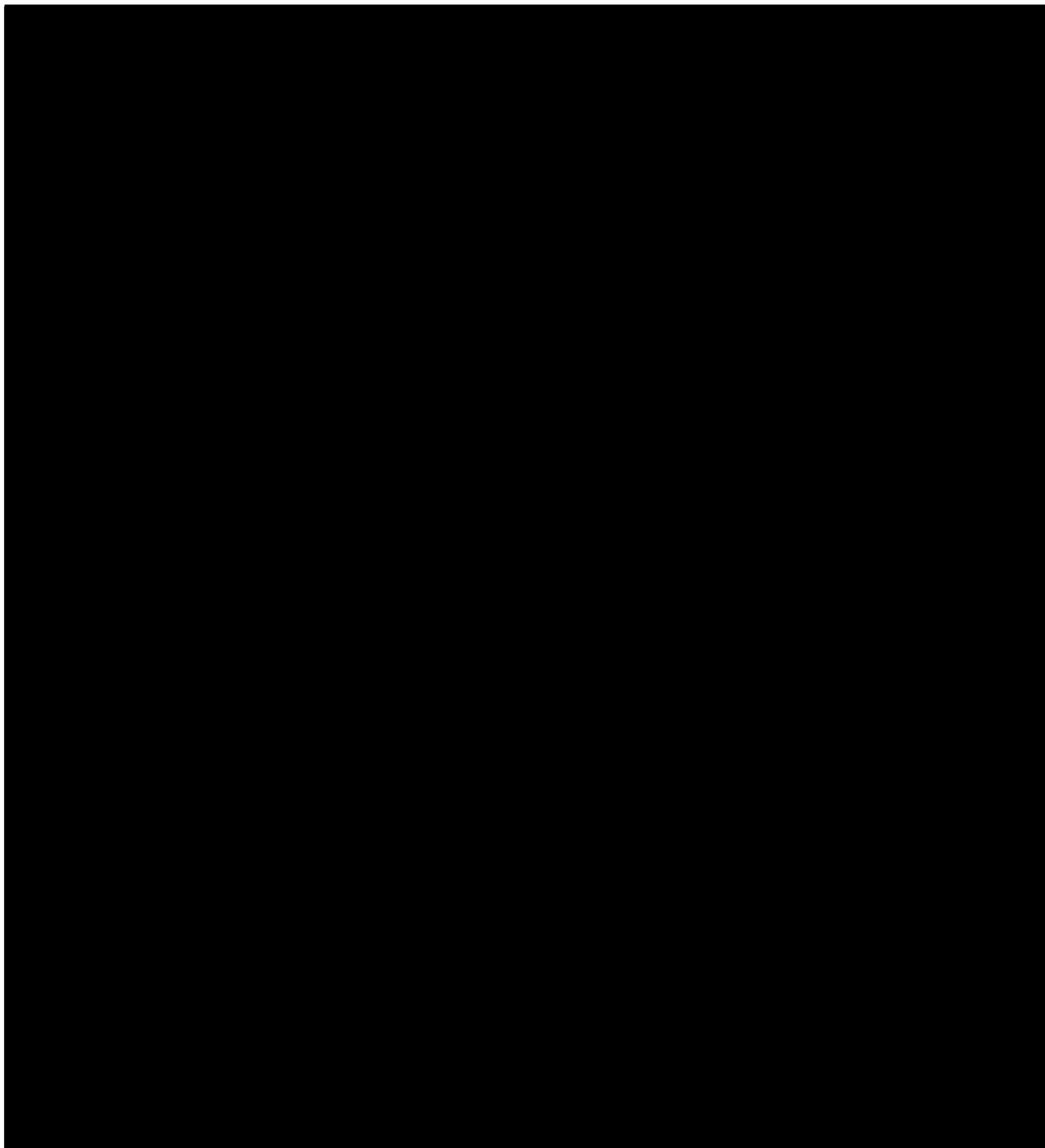

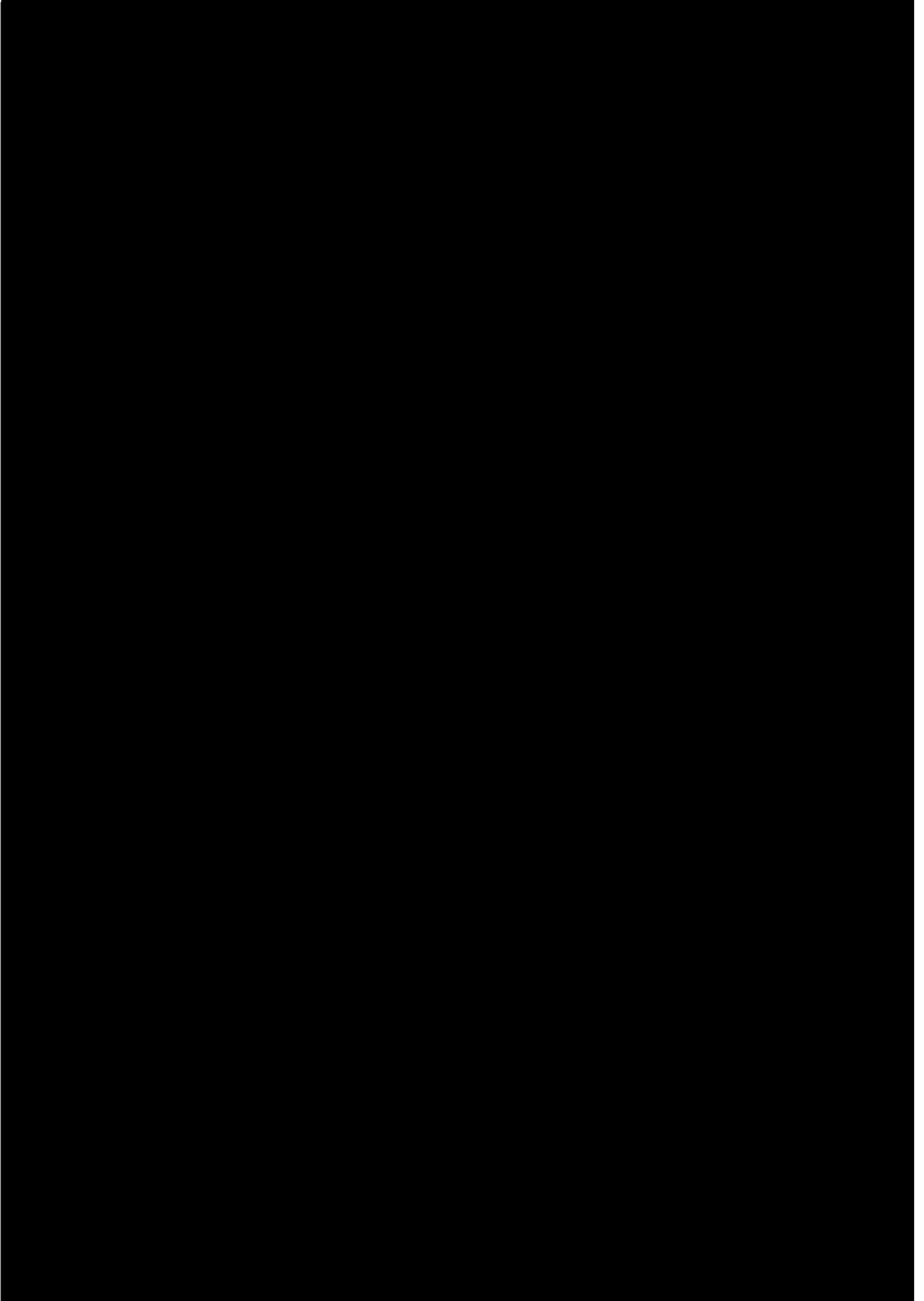

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CHAPTER I

INTRODUCTION

"To everything there is a season and a time to every purpose under the heaven: a time to be born and a time to die. . ."[1]

Eissler wrote that the time, or moment, of one's death was the most important and decisive in a man's life, far greater than the moment of conception which, like the moment of birth, was beyond evaluation and individuality.[2]

Recent statistics indicate that forty-six per cent of our population is under twenty-five years of age.[3] Great emphasis has been placed on youth almost to the exlusion of aging and dying as important and natural experiences in the life process. Feifel stated that one of the reasons our society rejected the aged was that they reminded us of death. He pointed out that professional people who came in contact with chronic and terminally ill patients noted similar avoidance tendencies in themselves.[4]

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[1] Ecclesiastes 3:1-2.

[2] K. R. Eissler, The Psychiatrist and the Dying Patient (New York: International Universities Press, Inc., 1955), p. 5.

[3] U. S. Bureau of the Census, Statistical Abstract of the United States 1970 (Washington, D.C.: Government Printing Office, 1970),p. 10.

[4] Herman Feifel. "Attitudes Toward Death," in The Meaning of Death ed. by Herman Feifel (New York: McGraw-Hill Book Company, 1965), p. 118.

Background

This investigator's interest in dying patients stems from numerous personal experiences encountered in twelve years of nursing. Nine of these years were spent on research units where care was given to patients with a variety of acute and chronic diseases for which the prognosis was uncertain. Many of these patients entered the hospital for investigational procedures such as kidney transplants, and more recently for heart transplants. On these units, the average length of stay was three times longer than on other units in the hospital.[5] Patients on these units often indicated an awareness of the possibility of their own deaths. This awareness could be attributed to the longer period of hospitalization, the exposure to the death of other patients during this period, and to the investigational nature of the research in which they were participating. Patients expressed their awareness in many ways. For example, one patient with carcinoid was deteriorating rapidly. As he was being weighed one morning, he began singing a familiar tune. The song was "Love Walked In and Drove the Shadows Away," except the words had been changed--the version sung by the patient indicated his awareness --"Death Came In and Drove the Shadows Away."

A female patient, who was chronically ill and had been on the unit six weeks, was approached by the head nurse and told that it was necessary to put male patients in her room; therefore, she would be moved to another room. This room happened to be the one closest to the nurses' station. When the patient heard this, she replied, "You'll not get me into that room. I've been here long enough to see that most

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[5]These data were obtained by review of medical records.

patients who go in there don't come out alive." This remark caused the head nurse to reflect upon her actions of the past. It had been the practice on the unit to move acutely ill patients closer to the nurses' station so that they could have closer supervision. Apparently this action had led the patient to whom the head nurse spoke to believe that this room was reserved for those who were dying. Could other patients have felt the same way? In reality, many did die in this room. Perhaps acutely ill patients who were moved into this room had misgivings also if they had made similar observations prior to becoming critically ill. What were their feelings?

After a death occurred on the unit, it was customary for the staff to proceed with their routine activities, acting as if nothing had happened. One patient who was aware of the death of a patient across the hall made this remark to the nurse who brought him his medications, "I hope that when I die someone will show a little more concern than you are showing over Mr. X.'s death."

Remarks like those already described and many others provoked a great deal of concern, and the head nurse decided to explore how the nursing staff felt about death and dying. A meeting was held to discuss their feelings about this subject. Interest was high and it soon became obvious that additional discussions were needed. Plans were made for three more sessions. These were attended by a sociologist, a hospital chaplain and a psychiatric nursing instructor. Following the last session, the staff expressed the opinion that these had been the most meaningful meetings ever held on the unit. Some of the personnel felt that they had become more aware of the dying patient's physical needs. Others thought more should be done to ascertain the emotional needs of the dying

patient. Most of the staff indicated that trying to determine the dying patient's emotional needs was the most difficult problem encountered in caring for these patients.

Kubler-Ross indicated how the dying patient could be helped: "When a patient is severely ill, he is often treated like a person with no right to an opinion...It would take so little to remember that the sick person too has feelings, has wishes and opinions, and has--most important of all--the right to be heard."[6]

The Problem

The problem to be investigated is: What are the emotional needs of patients, who are approaching death, as revealed by the patients themselves? The review of literature pointed out that almost all of the data published about the dying patient were the thoughts of those around him rather than his own thoughts. Since the patient is our concern, it would seem logical to ask him what his needs are.

Nurses recognize as one of their responsibilities that of assisting a patient toward a peaceful death when curative goals are beyond grasp. If the patient dies and his needs are not met, or his distress unrelieved, how could his death be peaceful? The investigator feels that one way by which death could be made more peaceful is by ascertaining the patient's emotional needs and trying to meet them.

Limitations

There are several limitations to this study. The sample was small; the patients were terminally ill; the duration of their illness varied;

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[6]Elisabeth Kubler-Ross, On Death and Dying (New York: The Macmillan Company, 1969), pp. 7-8.

the number of hospital admissions per patient varied; each patient had been attended by several physicians in the course of his illness; the effects of environmental factors upon the patients could not be determined; the investigator may have been unconsciously affected by the interviews.

Purpose

The purposes of this study are: (1) to determine the dying patient's emotional needs, (2) to determine if these needs are being met, and (3) to identify other areas for future investigation if these needs are not being met.

Webster's Third New International Dictionary of the English Language defines need as a "want of something requisite, desirable or useful." As situationally defined by Orlando, need is a "requirement of the patient, which if supplied, relieves or diminishes his immediate distress or improves his immediate sense of adequacy or well-being."[7]

Assumptions

There are two assumptions underlying this study: (1) Patients who are terminally ill want to talk about dying and their personal and unique feelings about it.[8] (2) Patients who are terminally ill will

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[7] Ida Jean Orlando, The Dynamic Nurse-Patient Relationship (New York: The Macmillan Company, 1951), p. 5.

[8] Gloria Francis and Barbara Munjas, Promoting Psychological Comfort (Dubuque: William C. Brown Company, Publishers, 1968), pp. 50-51.

express emotional needs only if their physical needs are being met satisfactorily.[9]

Definition of Terms

Throughout this study the following terms are defined in this manner:

terminally ill patient---	a patient whose condition is deteriorating and appears likely to result in death during the present hospital admission.
emotional need----------	a requirement of the patient, which when supplied, promotes his psychological well-being.[10]
present care-------------	the sum total of activities carried out by various hospital personnel and directly involving the patient during his current period of hospitalization.
environmental factors----	an accumulation of circumstances present in the setting in which the interviews were conducted and which may have affected the interviews adversely, such as noise level, lack of privacy, interruptions, and staffing problems.

Methodology

The method selected for this study was the exploratory case study. This method is appropriate when the purpose of the study is to gain familiarity with a phenomenon or to achieve new insights into it,

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[9] Based on A. H. Maslow's Human Motivation Theory which stated that man's basic needs were arranged in a hierarchy of prepotency, the physiological needs being the most prepotent. A. H. Maslow, "A Theory of Human Motivation," Psychological Review L (1943), 370-396.

[10] Adapted from Orlando's definition in The Dynamic Nurse-Patient Relationship, p. 5.

often in order to formulate more precise research problems, or to develop hypotheses. The major emphasis of exploratory studies is on discovery of ideas and insights.[11]

The case study approach is an especially appropriate procedure for evoking insights because the attitude of the investigator is one of alert receptivity, of seeking rather than testing. Another feature which makes the case study approach appropriate is the intensity of the study of the phenomenon selected for investigation. The investigator attempts to obtain sufficient information to characterize and explain both the unique features of the case(s) being studied and those which it has in common with other cases.

Selltiz stated that social scientists who used this approach often found that the study of a few instances produced a wealth of new insights, whereas a host of other instances yielded few new ones.[12]

The interview technique was selected for this study because it offered the opportunity for flexibility in eliciting information about complex, emotionally-laden subjects, or for probing the sentiments which may underlie an expressed opinion. It also permitted clarification of questions when necessary. The interview is also more personal and the interviewer has the opportunity to observe not only what the respondent said, but also how he said it.[13]

The investigator decided on the use of the interview technique exclusively for this study after attending a conference at the University

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[11]Selltiz, Claire, et.al., Research Methods in Social Relations (New York: Holt, Rinehart and Winston, 1959), p. 50.

[12]Ibid., pp. 60-61.

[13]Ibid., p. 242.

of Chicago where Dr. Elisabeth Kubler-Ross, who is well known for her work with dying patients, was one of the principal speakers. Her experience with the interview technique indicated that it was an effective tool.

A structured interview guide was prepared and pre-tested on five patients. It was found during this pre-test that a structured guide was too rigid, and the investigator was getting many "yes" and "no" responses from the patients; therefore, a different approach was warranted. A semi-structured interview guide[14] was prepared and pre-tested. The results were more productive because the investigator used her discretion in asking the question which seemed to be appropriate at any given time.

The interviews were recorded using a cassette recorder. To facilitate handling the analyses of the data, only one interview was recorded on each side of the cassette. There were no mechanical difficulties encountered during any of the interviews.

The population for this study was ten adult Caucasian patients admitted to The Medical College of Virginia Hospitals. Criteria for patient selection were: (1) the patient was terminally ill, (2) the patient was aware of his terminal status, (3) the patient was capable of verbalizing, (4) the physician consented to having the patient included in the study, and (5) the patient consented to participate in the study.

Although impossible to predict with accuracy, it was the intent of the investigator to include in the study only those patients whose condition was deteriorating during the present hospitalization, and who seemed likely to have a fatal outcome.

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[14]Appendix A, p. 36.

Patients who met the above criteria were found by referrals from three sources: nursing personnel, physicians, and other hospital personnel.

Data were collected from June 24, 1970, to December 1, 1970. After receiving the name of a patient who might be a candidate for the study, the investigator contacted the patient's physician to inform him of the study, to determine whether the patient met the first three criteria, and to ask permission for the patient to participate in the study. The physician signed the Physician Consent Form[15] and the Patient Consent Form.[16] The latter was signed by the physician and shown to the patient later so that he would be assured that the investigator had obtained the physician's consent. After receiving permission from the physician, the investigator visited the patient. She introduced herself in a similar manner to each patient.[17] The patient consent form was signed by the patient after he indicated that he would participate in the study.

The investigator was always in uniform during the initial visit with the patient, as well as during the interview.

The setting for nine of the interviews was in the patients' rooms. One interview was conducted in the lounge on the hospital unit. Of the ten patients interviewed, seven were in private rooms and three were in semi-private rooms (two patients were in four-bed units and one patient was in a two-bed unit). Other patients occupied the other beds in all shared facilities. Efforts were made to provide maximum privacy

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[15] Appendix B, p. 38.

[16] Appendix C, p. 39.

[17] Appendix D, p. 40.

during the interviews. No visitors or hospital personnel were present during the conversation between the patient and the investigator; however, there were some interruptions for medications, temperature recording, and physicians' visits.

Follow-up visits were made to each patient on the day after the interview to determine if there was additional information which the patient wanted to give the investigator. These visits produced information regarding only the physical needs of the patients and are not included in this study.

As soon as possible after the interviews, the recordings were transcribed by the investigator. Then the transcripts were reviewed independently by each member of the investigator's Graduate Committee and the emotional needs expressed during the interview were identified and classified by each reviewer.

CHAPTER II

Review of Literature

In recent years, there has been a substantial increase in socially acceptable inquiry into death and dying. This is a striking contrast to previous attitudes in our society in which this topic was regarded as socially unacceptable for discussion and very little could be found in the literature about the needs of those who were dying.

New trends were reflected by the establishment in 1968 of the Foundation of Thanatology, which is devoted to inquiries into death, loss, grief and bereavement. A non-profit organization, it serves the interdisciplinary needs of workers in the fields of the health professions, theology, psychology and the social sciences through an educational publication program.[18]

Many other developments reflect the widespread interest in death and dying. A recent book written by five eminent clinicians examined the psychological, sociological and physical aspects of death. Their focus was on the existential problem of dying and the interaction between the dying person and those around him during the last stage of his life. An extensive bibliography was also developed by the editor of this book.[19]

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[18]The Foundation of Thanatology, 630 West 168th Street, New York, New York.

[19]Leonard Pearson, ed., Death and Dying (Cleveland: The Press of Case Western Reserve University, 1969).

A developmental grant was recently awarded to the Yale University School of Nursing for an interdisciplinary study of the care of dying patients and their families. The project is being funded by a grant from the United States Public Health Service. This study seeks to understand the needs and wants of the dying patient and his family, and to identify patterns of patient care which are needed to meet these needs and wants. A secondary objective of the Yale study is to develop tools for recording actions and interactions in the care of the dying.[20] The principal investigator, Mrs. Florence Wald, stated that her bibliography to date consisted of 2,800 entries.[21] This reflects the extent of literature presently available on this subject.

In a study concerned with the emotional needs of terminally ill patients, Fisher found that dying patients, who were allowed to share their feelings about dying, showed the most improvement in behavior. This was linked to the emotional state of each individual patient. Her findings indicated that terminally ill patients have a need to talk about their approaching deaths.[22]

Lewis's study was concerned with the identification of the unmet needs of the dying patient. Her study consisted of interviews with twenty nurses to determine the needs they identified in dying patients.

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[20]American Nurses' Foundation, Inc., Nursing Research Reports (New York: American Nurses' Foundation, Inc., V, June, 1970), p. 4.

[21]Letter from Mrs. Florence Wald dated September 8, 1970.

[22]Jean Fisher, "Nursing Care of Terminally Ill Patients" (unpublished Master's thesis, Yale University School of Nursing, 1965).

Her findings showed that fifteen of the group, or 75 per cent, felt that dying patients needed more emotional support.[23]

In a study of 102 medical patients facing death, Hinton found that the degree of acceptance of prognosis was not related to sex, marital status, strength of religious faith, length of illness, or physical discomfort. Greater distress was experienced by those with dependent children. Hinton stated that patients wanted to know their prospects and that physicians should talk frankly with them so that the patients may gain peace of mind.[24]

Duff and Hollingshead found that when the patient had a poor prognosis, communication between the physician and the patient was altered, possibly to make the frustrations less evident or less painful, but this influenced the care the patient received. Evasions were used extensively. These evasions were the most evident when the dread of the illness was the greatest. Patients and professionals had a fatalistic feeling about cancer. They believed it commonly disabled, eroded, and tortured the body and ultimately killed. Among the twenty-one persons dying of this disease, evasions were used by the professionals in 86 per cent of the cases.[25]

At the University of Chicago, terminally ill patients volunteered to share their feelings about death and dying with medical and

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[23]Wilma Lewis, "Identification of the Unmet Needs in the Nursing Care of the Patient Who is Facing Death" (unpublished Master's thesis, University of North Carolina School of Nursing, 1965).

[24]John Hinton, "Facing Death," Journal of Psychosomatic Research X (1966), 19-28.

[25]Raymond Duff and August Hollingshead, Sickness and Society (New York: Harper and Row, Publishers, 1968), p. 368.

theology students, nurses, and social workers. This program, now in its fifth year, "has vanquished the conspiracy of silence that once shrouded the hospital's terminal wards. It has brought death out of the darkness."[26] The initiation of this program was met by stubborn resistance from other physicians, but once this obstacle was overcome, Kubler-Ross found that dying patients were quite willing to talk; moreover, they became the instructors for the program. In four years, 150 patients volunteered to express their feelings; only three patients decided not to participate in the program. Kubler-Ross found that the patient who was not told the truth about his illness always discovered the truth anyway and often resented the deception, regardless of however well meant. She concluded that the "dying are living too and are bitter at being prematurely consigned--by indifference, false cheerfulness and isolation--to the bourn of the dead." They do not fear death, but rather dying, a process almost as painful to see as to endure, and one on which society, and even medicine, so readily turns its back.[27]

The University of Chicago held an educational institute sponsored by the Kramer Foundation in January, 1970. The purpose of this two-day conference, which this investigator attended,[28] was to discuss problems of dying patients, their families, and the professional staff who cared for them.

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[26] "Dying," Time Magazine, October 10, 1969, p. 60.

[27] Ibid.

[28] Appendix E, p. 41.

At the University of Maryland, Dr. Dan Leviton taught a two-week course entitled "Death Education and Suicide Prevention" in July, 1970.[29] This was the only course to date in death education found during the investigator's search of the literature.

In March, 1970, the Department of Nursing of The Virginia Commonwealth University Hospitals sponsored a one-day in-service program on The Care of the Terminally Ill Patient.

At the same University, the Chairman of the Department of Patient Counseling, Professor A. P. L. Prest, has written a book, The Language of the Dying.[30] It consists of clinical case studies of people in the death process and how they react to it.[31]

Many physicians and nurses agree that caring for the dying is emotionally upsetting and traumatic. As a result, physicians frequently elect to specialize in branches of medicine which will limit their exposure to the dying. Nurses admit their preference for units where there is little confrontation with death. Many of those who do care of the dying have developed methods of coping with the situation. The most frequently used method is to avoid contact with patients who are unaware of

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[29]Letter from Dr. Dan Leviton, March 2, 1971. According to Dr. Leviton, an article describing this course was to appear in the April, 1971 issue of the Journal of American College Health Associations.

[30]Published in German by Vandenhoeck & Ruprecht, Gottingen, Germany, 1970.

[31]Interview with Professor A. P. L. Prest, Richmond, Virginia, March 12, 1971.

their impending death and question the staff, with those who have not yet "accepted" their approaching death, and with those whose final hours are accompanied by great pain. This tendency is recognized by physicians and nurses, and as a result they are disturbed by their own ineptness in caring for those who are dying.[32]

At a time when he needs the most support, the dying patient often is left alone. Glaser and Strauss observed that not only does the lack of communication produce isolation, but the practice of isolating a dying patient during his last days is not unusual. Moving him closer to the nurses' station often frightens the mentally alert patient as well as interrupts satisfying relationships with other patients on the ward. If he is disturbing to other patients, he may find himself isolated in a private room.[33] This may result in lack of contact with others and cause him to feel abandoned and rejected.[34]

Tolstoy discussed this isolation in The Death of Ivan Ilyich: "What tormented Ivan Ilyich most was the deception--their not wishing to admit what they knew, but wanting to lie to him, and forcing him to participate in that lie . . .and he had thus to live all alone on the brink of an abyss with no one who understood or pitied him."[35]

It was suggested by Quint, the outstanding nurse authority in this area, that "the dying patient--the forgotten man in the hospital--can well

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[32]Barney Glaser and Anselm Strauss, Awareness of Dying (Chicago: Aldine Publishing Company, 1965), pp. 3-5.

[33]Barney Glaser and Anselm Strauss, Time for Dying (Chicago: Aldine Publishing Company, 1968), p. 168.

[34]Herman Feifel, ed., The Meaning of Death, p. 125.

[35]L. N. Tolstoy, "The Death of Ivan Ilyich," in The Works of L. N. Tolstoy (New York: Charles Scribner's Sons, XIV, 1904), 96.

use an ally whose goal is to help him live with his human problems and the personal and social strains associated with his outcast position." She suggested further that professional nurses could contribute to improving the care of the dying if they were willing to assume more active roles in communicating with dying patients.[36]

The philosophy of caring for patients in the last stages of life at a small hospital outside London is such that the staff look upon these patients as "persons in distress" and "concentrate on giving them relief." Saunders has written extensively about her ideology and operational philosophy at St. Joseph's Hospital. Her philosophy is that the "care of the dying demands all that we can do to enable patients to live until they die. . .and includes the care of the family, the mind, and the spirit as well as the care of the body." Consequently, the establishment of the patient's trust involves the willingness to openly discuss it. Most of the patients at St. Joseph's are aware of their approaching death.[37] Saunders also felt that the patient's awareness of his terminal status happened quietly and without fuss and in its own time.[38]

Green believed that silence was more cruel than the truth. It was cruel because it blocked all possibility of genuine comfort and forced the patient to face life's last great event alone. However, physicians are reluctant to tell patients the truth.[39] Physicians themselves have

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[36]Jeanne C. Quint, The Nurse and the Dying Patient (New York: The Macmillan Company, 1967), p. 12.

[37]Cicely Saunders, "The Last Stages of Life," American Journal of Nursing, LXV (March, 1965), 70-75.

[38]______________, "The Moment of Truth," in Death and Dying, ed. by Leonard Pearson, p. 55.

[39]Elearnor P. Green, "How Can We Help the Dying?" Consultant (June, 1967), p. 46.

indicated that they would wish to be told the truth if they were the patient. In a 1961 questionnaire in which 1,300 physicians responded, 92.1 per cent of them said, "Yes," to the question, "If you had a malignancy, would you wish to be told the truth?" To the question, "When a diagnosis of cancer is established, do you tell the patient the truth?", only 57.1 per cent of the physicians responded that they told the patient the truth.[40] Green asked, "Should not physicians also adhere to the Golden Rule?"[41]

Field stated that running away from the patient and denying the reality of his condition merely intensified his anxiety and left him alone with his problem. "If we can learn to listen to the patient speak of his fear of impending death, neither running away from it nor denying it, that in itself may be rendering a service of real value. By staying with the patient, we not only give him an opportunity to vent his feelings, but at the same time we affirm our regard for him as a person, our respect for what he is trying to tell us, and our understanding of, and sympathy with, his feelings.[42]

Van den Bergh said, "We must overcome our own inhibiting emotions if we are going to look directly and objectively at the subject and collect

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[40]"Pulse of Medicine Poll," conducted by Medical Tribune, Inc., May 8, 1961, pp. 1, 10.

[41]Green, "Dying," p. 46.

[42]Minna Field, _Patients are People_ (New York: Columbia Universities Press, 1953), p. 149.

facts. Therefore, we must have the courage to spend time listening to what the dying patient is saying while he is dying."[43]

Francis and Munjas stated that even though not one of us could share in another's death, one could share in another's dying. Moreover, they stated that this was a professional obligation in spite of the fact that the nursing profession's Code of Ethics[44] neither alluded to nor referred to responsibility to the dying patient.[45]

Kneisl stated that a philosophy which attempted to keep the truth from patients is based on the assumption that all individuals in reality do not want to confront the issue of dying. Inadequate communication among health team members is a serious obstacle to thoughtful care of the dying. Too often the physician's decision not to reveal the true diagnosis to the patient is not relayed to the nurse. The patient usually turns to the nurse for information which she may not have, or if she does, she is expected by the physician and/or the patient's family not to reveal it.[46]

Quint stated that the problems related to death have become more and more complex due to social change and scientific advances in this century. People are living longer and accompanying the longer life span

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[43]Richard Van den Bergh, "Let's Talk About Death," American Journal of Nursing, LXVI (January, 1966), 70-73.

[44]American Nurses' Association, Code of Ethics (New York: The Journal of Nursing Company, 1960).

[45]Gloria Francis and Barbara Munjas, Promoting Psychological Comfort (Dubuque: William C. Brown Company, Publishers, 1968), pp. 50-51.

[46]Carol Ann Kneisl, "Thoughtful Care for the Dying," American Journal of Nursing, LXVIII (March, 1968), 550-553.

is an increase in chronic diseases. Improvements in symptomatic therapy have enabled persons with these diseases to be admitted several times to the hospital before death occurs. Patients, who were formerly considered to have a fatal disease, are now entering the hospital for investigational procedures such as kidney transplants which are almost commonplace in large hospitals and research centers. In many hospitals today, nurses are caring for patients who face the possibility of imminent death because the outcome of these procedures cannot be predicted.[47]

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[47] Quint, The Nurse and the Dying Patient, p. 249.

CHAPTER III

PRESENTATION, ANALYSIS AND INTERPRETATION OF DATA

The following information is a summary of the data obtained from each patient during a semi-structured interview. The exact transcript of each interview is available in the Appendix. A summary of pertinent personal information about the study patients appears in the Appendix.[48]

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[48]Appendix F, p. 42.

Analysis of Interview, Patient A

Patient A expressed denial throughout the interview. Her family seemed to offer support, even though she would not verbalize her feelings about her condition to them. Her son and grandchildren visited frequently and her husband came every day. She expressed some of her feelings to the investigator because the investigator was not a family member.

The presence of hope was indicated on several occasions. She would not consider suicide because she loved life too well, and she might get better.

She indicated a need for companionship. She wanted to be in a room with other patients because the distractions helped to enhance her denial and repression. Being in a private room would allow too many opportunities to think about herself. She needed to talk about events which gave her pleasure in the past and being with others gave her this opportunity.

The need to feel generative was also expressed. Her family was the bright spot in her life, and she was proud of what she had taught her grandchildren. Also, she gained satisfaction and a sense of achievement by "helping to make a better nurse."

The need for independence was expressed. The patient needed some control over her environment, even though she was dependent upon others for her care.

The need to re-establish ties with a church was noted. She seemed apologetic when she said she did not belong to any church currently and indicated that her previous relationship had been a meaningful one.[49]

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[49]See Appendix G for transcript of interview with Patient A, pp.44-52.

Analysis of Interview, Patient B

Patient B had lost hope. He felt from the very beginning that all of the tumor had not been removed. The drugs that were being used on him were only for experimental purposes. He seemed to need companionship and the need to feel generative. Although he had no children, his two nieces were "just like my children." They would insure his immortality. This patient needed to strengthen his religious convictions. He seemed to have a lot of guilt feelings in this area. He expressed the need to know how much longer he would live. He acknowledged suicidal intentions, but was afraid to carry them out. He also expressed the need to know what his diagnosis was, then qualified this statement when he said, "No one wants to know he has cancer."[50]

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[50]See Appendix H for transcript of interview with Patient B, pp. 53 - 58.

Analysis of Interview, Patient C

Patient C demonstrated denial several times. He needed to feel generative and was delighted to discuss his children's accomplishments. His religious convictions were strong, and he felt that he had been "born again." Before his religious convictions had been re-established, he indicated that he had thought of suicide. This patient seemed to need to express his feelings about his day-to-day needs, rather than his future needs.[51]

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[51]See Appendix I for transcript of interview with Patient C , pp. 59-62.

Analysis of Interview, Patient D

Patient D was angry because he realized he was not getting better. He was also angry at his physician, whom he felt had not listened to him.

He expressed denial on several occasions. He stated that his present condition was due to not being able to eat, rather than a recurrence of his previous tumor. He also associated the decrease in the amount of pain medications which he was taking with improvement in his condition. He attributed his shortness of breath to the sleeping pill he received every night, and his pain was caused by eating. He indicated the need for companionship and the need to share his feelings with someone who was interested.

He was very much alone and had no place to go or anyone to care for him. He was resigned to being in a hospital or a nursing home.

He needed to express some degree of independence by exerting some control over his environment.

He lacked hope and expressed suicidal thoughts.[52]

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[52] See Appendix J for transcript of interview with Patient D, pp. 63-70.

Analysis of Interview, Patient E

Patient E conveyed the message of hope throughout the interview. She also expressed the need for denial. She did not want to know the reasons for the different treatments she had had because she probably could not manage any more details. She attributed her pain to the breakdown of her tumor and this meant the chemotherapy was successful.

This patient had strong religious convictions, which provided a great deal of support and may have provided a glimpse of immortality. She also received support from her family.

She expressed the need to feel as independent as possible. She feared that the staff might not understand her problem and show pity for her, and this would break down her denial. She wanted to share her feelings with someone and she wanted companionship--"It helps to know that someone is there." She did not wish to be in a room with another patient because this might be too depressing and might also break down her denial.

This patient expressed the need to know what was going on, although she did not want too many details.[53]

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[53]See Appendix K for transcript of interview with Patient E, pp. 71-76.

Analysis of Interview, Patient F

Patient F lacked hope. She seemed to be resigned to the fact that she was not improving. She seemed ambivalent at times about her knowledge. She could not tell the investigator why she preferred to know what was wrong with her. She appeared withdrawn at times and avoided the investigator's questions as much as possible.

This patient had strong religious convictions, and it seemed that she was receiving more support from them than from any other source.[54]

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[54]See Appendix L for transcript of interview with Patient F, pp. 77-81.

Analysis of Interview, Patient G

Patient G needed to know the truth about his condition, and he seemed to be facing the future calmly, although he was mourning his own death.

He lacked hope because he knew very little could be done for him.

He received a lot of support from his family and his religious convictions.

He showed some denial when he said he was "...just as contented as can be here," and again when he said, "My days are limited, but it doesn't bother me."[55]

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[55]See Appendix M for transcript of interview with Patient G, pp. 82-86.

Analysis of Interview, Patient H

Patient H expressed the lack of hope throughout the interview. She never felt that she would recover from her illness. However, she felt the need to "put up a good front" to spare the feelings of others, as well as to maintain her own defenses. She needed to discuss her feelings with someone who was not a family member because she did not want to burden them.

She was fearful of prolonged suffering and the effect it would have on herself, as well as her family. Because of her fears, she had considered suicide. Her guilt feelings about this were increased by her lack of stable religious convictions. She was depressed and despondent. She needed love and understanding and something for which to live. She needed to know that her feelings were normal and that other patients who were critically ill had expressed similar feelings.

She needed to know more about the side effects of her medications, since they seemed to cause her a lot of anxiety.

She was very frightened and lonely.[56]

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[56] See Appendix N for transcript of interview with Patient H, pp. 87-94.

Analysis of Interview, Patient I

Patient I expressed the presence of hope. She felt she would benefit from the treatments she was receiving. She also indicated the need to know, even though she did not ask her physician what melanoma meant. Her religious convictions gave her a great deal of support. She had put her faith in God, and she was sure He would help her. She needed companionship because when she was alone, she worried about her condition, and this affected her ability to cope.

She needed to keep the discussion about her condition superficial, and would not share her feelings with the investigator because it might be painful as well as threatening to her defense system.[57]

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[57] See Appendix O for transcript of interview with Patient I, pp. 95-100.

Analysis of Interview, Patient J

Patient J expressed the need to talk about her illness with other people who had the same problem, as well as the investigator. She needed to share her accomplishments. She needed to feel that she was helping others. She had a strong faith in God and a great deal of hope. She needed reassurance that her death would be dignified. She also needed companionship, which her family provided, and she needed doctors and nurses who were compassionate and understanding. She seemed to have accepted her condition better than her family had. She talked about death explicitly and discussed her own death briefly. She used a multiplicity of defense mechanisms--denial, identification and repression.[58]

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[58] See Appendix P for interview with Patient J, pp. 101-104.

The data presented revealed that nine of the study patients discussed their feelings about death and dying; however, this discussion was not specifically about their own death with two exceptions. Patients B and J spoke about their own death. Patients A, C, D, E, G, H, and I spoke implicitly about death but not at all about their own death. Patient F avoided discussing this subject altogether.

The need to share their feelings with someone who was not close to them was expressed by two patients, A and B, who wanted to avoid causing their loved ones more worry. Also, these same patients expressed the need to "put up a good front" for the additional purpose of sparing their loved ones' feelings.

All of the patients interviewed expressed the need for denial; however, the degree of denial varied from patient to patient. Because of the small number of patients studied, no correlation could be determined between denial and any of the other factors, such as age, marital status, length of illness, number of children, or religion.

The need for companionship was expressed by all of the patients studied. Even the patients who were in private rooms indicated that they enjoyed the company of others. These patients, B, E, F, G, H, and J, preferred having a private room primarily to avoid the possibility of being with another patient who might be quite ill. This would be "too depressing." They also expressed the need for privacy.

The need for hope was exhibited by five patients, A, C, E, I, and J, and this seemed to give them strength to cope with their problems. Hope had been lost in five patients, B, D, F, G, and H, and they seemed resigned to the fact that they were not improving.

The need for knowledge refers to the finding that the patients indicated a need for information about the medicines they were receiving and an explanation about the side effects of these medicines. Furthermore, each patient expressed concern about the investigational nature of his/her medical care and prognosis. Some of this knowledge seemed to be needed by all of the patients.

Suicidal thoughts were expressed by four patients, B, C, D, and H. It was also revealed during the interview that these four patients had experienced difficulty with their spiritual needs. Patients B and H indicated a great deal of inner turmoil because of their spiritual problems. Patient C indicated that his suicidal thoughts prevailed prior to solving his spiritual problems. Patient D had not been associated with his church for many years. Furthermore, two of the four patients who expressed suicidal thoughts were very much alone, having neither spouse nor children, Patients D and H. Patient B, although married, had no children, but stated he had two nieces who "are just like my children." Patient C had been married twice and two of his children were born to his deceased first wife. Another child was born to his second wife during her previous marriage. All of the children were grown and living outside the patient's home.

These data suggest there might be a correlation between suicidal thoughts and the spiritual and generativity needs of the patients. However, no conclusion could be reached because of the small number of patients studied.

CHAPTER IV

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

This was an exploratory study to determine the emotional needs of terminally ill patients as described by the patients themselves. The review of literature revealed that most of the data published about the dying patient were the thoughts of those around the patient rather than the patient's own thoughts.

The investigator interviewed ten adult Caucasian patients who were aware of their condition.

The emotional needs revealed were the need to discuss their feelings (nine patients), the need for denial (ten patients), the need for companionship (ten patients), the need for hope (five patients), and the need for knowledge (ten patients). These data support Kubler-Ross's findings.[59]

In addition to the needs already described, which were common to most of the patients, there were many other expressed needs which were unique from one patient to another. This supports the fact that individuals, sick or well, have individual needs which must be met on an individual basis. As members of the health profession, we must be constantly alert and receptive to the clues which each individual patient gives.

The findings of this study have several implications for nursing practice, nursing education and nursing research.

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[59]Elisabeth Kubler-Ross, loc.cit., pp. 229-237.

First, in terms of nursing practice, patients do need to discuss their feelings about death and dying with someone. Nurses should be alert for clues which indicate that the patient wants to discuss his feelings and they should also make themselves available to listen to what the patient wants to say. Although the patient may be denying the reality of his condition, he still needs to verbalize his feelings, and can do so without breaking down his defense mechanisms. Secondly, nurses can answer many of the patient's requests for more information about his care, assuming that she has the information.

For nursing education, the author recommends that interviewing techniques be taught early in the nursing curriculum. Much time is spent by nurses in interviewing patients; therefore, it is necessary that they become more knowledgeable in this area. Seminars on death and dying should be included early in the curriculum of nursing students and should continue at intervals throughout the program.

For nursing research, the author suggests that: (a) this study be replicated, using a larger population in order to validate these findings; (b) a second person would be utilized to do the interviewing to minimize possible bias; (c) a future study would include patients from different ethnic groups to determine what influence, if any, race has upon the results; (d) a study of people to determine if a relationship exists between persons who have expressed suicidal thoughts and persons who have expressed fluctuations in their religious convictions; (e) a comparative study of people with and without spouse or children to determine if suicidal thoughts are more prevalent in either group; (f) a comparative study of private and non-private patients to determine what influence, if any, socio-economic status has upon one's emotional needs.

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MEETINGS:

"The Dying Patient and His Family." Sponsored by the Kramer Foundation, January 16-17, 1970, at the University of Chicago, Chicago, Illinois.

Appendix A

Interview Guide

1. How sick are you?

2. How long have you been in the hospital?

3. Why did you pick this hospital?

4. When did you learn the nature of your illness?

   A. Who told you the nature of your illness?
   B. What did this mean to you?
   C. Would you have preferred to have learned in a different way?

      1. If yes--please explain.
      2. If no--please explain.

5. Do you have pain?

   A. If yes--how is it usually relieved?
   B. Does it interfere with your sleep?
   C. Does anything else interfere with your sleep?

6. Do you consider yourself to be a nervous person?

   A. Do you feel all wound up inside?
   B. Do you ever get so nervous that you shake?

7. Do you have any trouble with being depressed, or with being very sad and down in the dumps?

   A. Do you cry or feel like crying and cannot?
   B. Do you ever get so depressed that you feel like killing yourself?

8. Do you understand the reason for the various treatments which you are receiving?

9. Are you uncomfortable during any of these treatments?

10. Do you prefer to be in a room by yourself or to share one with other patients?

    A. If alone--explain why.
    B. If with others--explain why.
    C. Have you been moved recently?

       1. Why?

11. What is your religious preference?

12. Have your religious beliefs been helpful to you during your illness?

    A. If yes--in what way?
    B. If no--please explain.

13. Does your minister/priest/rabbi visit you?

    A. If yes--how often does he visit?
    B. If no--please explain.

14. Has a hospital chaplain visited you?

    A. If yes--was his visit helpful?
    B. How was it helpful?
    C. If no--would you like for him to visit you?

15. Tell me about your family.

16. Do they visit you often?

    A. If yes--which member, how often, how long does he/she usually stay?
    B. If no--please explain.

17. Have you discussed your feelings about your illness with anyone?

    A. If yes--could you tell me about it?
    B. If no--why not?

18. How do you feel about this interview?

    A. If helpful--in what way?
    B. If difficult--in what way?

19. Do you have any ideas of how others like you might be helped?

20. How can I be of further help to you?

APPENDIX B

Physician Consent Form

Dear Dr.__________________:

I am a graduate student in nursing and elected to do my thesis on identifying the emotional needs of patients who are terminally ill. To be included in this study, patients must be aware of their terminal status and be willing to discuss their feelings. It is recognized that some patients may not want to discuss their feelings; therefore, only those who have indicated that they would like to discuss them will be interviewed. The interview will be recorded; however, patients' names will not be used in the findings of the study.

A copy of the interview guide is attached for your information. If you have any questions regarding this study, please do not hesitate to get in touch with me. My number at work is extension 4601 and at home 358-9418. Because of the ethical issues involved with a study of this nature, the proposal was submitted to the Committee for the Conduct of Clinical Research for approval. Your approval also is essential for patient participation. If you are willing for me to include your patient, ____________________________, in this study please sign below. Thank you for your cooperation.

____
(Mrs.) June H. Turnage, R.N.

____
(Physician's Signature)

____
(Date)

APPENDIX C

PATIENT CONSENT FORM

I, ______________________________________, hereby give my permission to participate in a study conducted by Mrs. Turnage. I understand that the interview will be recorded and that my name will not be used in any of the findings of this study.

____
(Patient's Signature)

____
(Physician's Signature)

APPENDIX D

INVESTIGATOR'S INTRODUCTION TO PATIENT

"Hello, Mr., Mrs., or Miss___________________________, I am Mrs. Turnage, and I am conducting a study to determine the needs of patients in your condition. I have been a nurse for twelve years, and I have found that patients would like to talk about their feelings, but seldom have the opportunity to do so. I also believe that nurses could do more to help patients if they know how patients feel about their illnesses. If you would like to talk with me, I will come back tomorrow. Our conversation will be recorded, but your name will not be used in the findings of this study."

Kramer Foundation Educational Institute

TOWARD THERAPEUTIC LONG TERM CARE

Certificate of Completion

Presented to MRS. JUNE H. TURNAGE

of Health Sciences Center of
Virginia Commonwealth University

who attended THE DYING PATIENT AND HIS FAMILY

held at University of Chicago
Center for Continuing Education

date January 16-17, 1970

KRAMER FOUNDATION

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APPENDIX F

SUMMARY OF PERSONAL INFORMATION ABOUT THE STUDY PATIENTS

Patient	Age	Sex	Marital Status	Number of Children	Religion	Diagnosis	Date of Diagnosis	Interview Setting	Date of Interview	Date of Death
A	68	F	Married	1	Baptist	Cancer of the Breast	1965	W-15, 4-bed room	6/24/70	7/9/70
B	68	M	Married	0	Catholic	Cancer of the Lung	1970	W-15, private room	7/14/70	*7/70
C	58	M	Married	3	Methodist	Cancer of Maxillary Sinus	1968	W-15, 2-bed room	7/16/70	9/24/70
D	69	M	Single	0	Presbyter-ian	Cancer of the Larynx	1969	W-15, 4-bed room	9/2/70	12/14/70
E	23	F	Single	0	Baptist	Cancer of the Ovary	1968	W-16, private room	9/2/70	10/12/70
F	58	F	Widowed	4	Seventh-Day Adventist	Lymphosar-coma	1962	North-8 private room	9/9/70	*3/19/71
G	64	M	Married	1	Methodist	Cancer of the Colon	1965	W-16, private room	10/30/70	2/27/71
H	50	F	Single	0	Church of Christ	Cancer of the Breast	1968	W-16, private room	11/2/70	**12/70
I	63	F	Widowed	3	Christian	Melanoma	1962	W-4, Lounge	11/30/70	***
J	66	F	Married	2	Episcopa-lian	Cancer of the Ovary	1968	Clinical Ctr. private room	12/1/70	Living

* Expired in Nursing Home ** Expired in Another Hospital ***Expired Elsewhere, Date not Available

The following interview transcripts are unedited and unabbreviated and reveal only the verbal communication which took place between the patient and the investigator. What cannot be shared with the reader is the non-verbal communications which occurred during such an experience.

The parentheses were inserted by the investigator to assist the reader's comprehension.

APPENDIX G

Interview with Patient A

Patient A was in bed watching television, which she turned off before the interview began. The curtains were closed around the bed to provide as much privacy as possible, but the physical setting was far from ideal. The noise level in the room at times was quite high. The patient responded easily to all questions except when she talked about her family; when they were mentioned she became tearful. It was noted that she was reluctant to say the word "cancer" aloud--she looked around as if someone else might be listening and then whispered the word. At times, she seemed to be uncomfortable as a result of back pain. She was restless in the bed and grimaced occasionally.

INVESTIGATOR: "Mrs. A., how long have you been in the hospital?"

PATIENT: "This time it's been three weeks today."

INVESTIGATOR: "How far back does your illness go?"

PATIENT: "It goes back to 1965. I went to the doctor about my back. He examined me and he was more interested in my breast so he told me he was going to remove the nipple and if he had to go further, he would, so he did and removed the whole breast. Well, for a long time after that my back didn't get any better and then the doctor was coming and giving me hormone shots. They didn't help, so Dr. H. recommended that I come to see Dr. M. That was in 1967. I had gotten so bad then that I couldn't even walk so I came to the hospital in October, 1967, and I left in April, 1968."

INVESTIGATOR: "You were here how long that time?"

PATIENT: "Five and a half months. Dr. M. got me back on my feet and got me walking which I was thankful for and I've been

seeing her (Dr. M.) since then, once a week, or every two weeks for medications. This past time when I came up I was feeling so bad that I couldn't get away again. Another time before this I came up for a check-up and Dr. M. was away on vacation and Dr. R. saw me and he wouldn't even let me go home. This was last July--I had phlebitis. This kept me in a long time. Then I was back last January for a month. I have had phlebitis several times but when I was here in January I had lost complete use of my right hand--it was numb and I talked like I had a mouth full of marbles, which I guess I do now. I was afraid it was a stroke, but she (Dr. M.) said it was some kind of spasm. I got the use back in my hand; of course, it's not as good as it was, but I got it back. I've been in here so many times that I can't remember what they were all for. I've had phlebitis several times."

INVESTIGATOR: "It sounds like phlebitis has caused you a lot of trouble."

PATIENT: "Well, it looks like everything has. Last night they gave me a liver scan. I know I haven't been drinking like I should."

INVESTIGATOR: "Mrs. A., what is wrong with you? Can you tell me?"

PATIENT: "No, because I haven't asked."

INVESTIGATOR: "Do you have any feelings about this--do you want to know, or do you suspect?"

PATIENT: "I suspect but. . .knowing what Dr. M. does. . ."

INVESTIGATOR: "Can you tell me what she does?"

PATIENT: (There is a long pause at this point. The patient looked around as if to be sure that no one else was listening. Then she whispered.) "Well, I know she's in cancer research. I feel like what I don't know won't hurt me. I can think, you know, but if I come out and ask and know it. . ." (Patient is tearful at this point.)

INVESTIGATOR: "Do you feel like it would hurt you more if you knew exactly what was wrong with you?"

PATIENT: "I do. I feel like it wouldn't help me to know."

INVESTIGATOR: "Why--do you worry a lot?"

PATIENT: "Just recently. I never did worry much and I'm different this time than I've ever been because I've always kept busy. I guess she (Dr. M.) told you that I sit in bed and crochet all the time. This time I'm not up to doing any of it. . .I just don't feel like it."

INVESTIGATOR: "Well, I know she's (Dr. M.) really trying."

PATIENT: "She's been mighty good to me."

INVESTIGATOR: "Is there anything in the hospital which you would like to see changed? Is there anything that really bothers you?"

PATIENT: "In the hospital the one thing that really bothers me is calling and having to wait. Of course, I realize they (nursing personnel) need help awfully bad, but calling and having to wait so long, especially when they give you a fluid pill! But I can get up now and take care of myself, but I have to get around and get the curtains pulled and I can do that as long as I can hold on to something. But she (Dr. M.) had told me she didn't want me to try to do any walking around because I might fall. She's (Dr. M.) cautioned me so much about falling, so I try to take care of that. This morning when I got up, I wanted water to wash. I'm so slow that I'd like to get it early before they (nursing personnel) change (end their tour of duty). It's hard to get them to do it and when the regular girl comes in she has to take temperatures and all and that makes me kinda late. My neighbor (one of her roommates) has been giving me water. I got up this morning and got the water and managed to get it here but the nurse gave me the dickens for it--'Don't you do that again.'"

INVESTIGATOR: "You just can't win, can you?"

PATIENT: "No. Since it does take me so long to bathe, I'd like to get it over with and I get so short of breath that I'd like to bathe and relax awhile before I have breakfast."

INVESTIGATOR: "I think that's a legitimate complaint. Have you talked to any of the nurses about this?"

PATIENT: "No, I haven't."

INVESTIGATOR: "Well, I think that's something we can bring to their attention. Tomorrow you'll have a student with you and they spend time in conference talking about ways they can help you and this should be put on your Kardex--your care plan--and hopefully you'll get the basin of water before the night staff leaves."

PATIENT: "Well, I would like for them to do it because I am so slow and I really would like it. All the times before when I was in the hospital, I got up about six o'clock in the morning to get bathed, and now I wake up about six-thirty, and if I had my water around seven--but that makes it bad because that's the time they're changing, isn't it? So if I could get it earlier it would be better."

INVESTIGATOR: "Is anything particular bothering you?"

PATIENT: "You mean is anything worrying me?"

INVESTIGATOR: "Yes, at home or here in the hospital?"

PATIENT: "No. I get provoked with being in the hospital and I get provoked when I call them (nursing personnel) to pick up a dirty bedpan and they won't come get it. I fuss about that. I fussed about it the other night."

INVESTIGATOR: "Did it get results?"

PATIENT: "It did that. I kept calling. I think I called three times. I said you'd better get in here and pick it up or else I'm going to call every five minutes. So they did."

INVESTIGATOR: "Mrs. A., have you talked with your husband about your illness very much?"

PATIENT: "No!" (said emphatically)

INVESTIGATOR: "Could you tell me why you haven't?"

PATIENT: "Because he worries."

INVESTIGATOR: "He worries and you worry."

PATIENT: "I just recently got to the point where I worry but he worries and I don't say anything to him."

INVESTIGATOR: "Have you ever wished you could talk to him more about this, or do you prefer not to?"

PATIENT: "No, because I don't want to cause any more worry than I have to. He's mighty good to me and has been taking care of me and looking out for me. He does all the cooking and cleaning, so I don't have this to do."

INVESTIGATOR: "Mrs. A., going back to your first operation--you told me the doctor said he may have to go further. Did he tell you why he went further?"

PATIENT: "No."

INVESTIGATOR: "He did not? But you felt like you knew what was wrong, is that right?"

PATIENT: "Yes. . ."

INVESTIGATOR: "Since you've been coming to Dr. M., what treatments have you been getting?"

PATIENT: "Well, she's been putting medicine in my veins and I've been taking prednisone and Orinase all along and potassium."

INVESTIGATOR: "Do you know why you were getting these drugs or how they affected you?"

PATIENT: "I know that the prednisone caused sugar--now I've got diabetes too, but I couldn't understand the diabetes business because no one in our family ever had it."

INVESTIGATOR: "It's caused by the prednisone. If it could be stopped, the diabetes would clear up. It's one of the side effects of this drug. It causes you to spill sugar in your urine, but that's not so bad."

PATIENT: "I didn't know--she (Dr. M.) told me it would cause sugar. I did know you could take diabetes by not taking care of yourself. I do know it runs in families and there's never been any in our family."

INVESTIGATOR: "Do you have children, Mrs. A.?"

PATIENT: (Patient's facial expression changed when children were mentioned and she began to smile.) "One; one son."

INVESTIGATOR: "How old is he and where does he live?"

PATIENT: "In R., he's 43."

INVESTIGATOR: "Do you have any grandchildren?"

PATIENT: "Three."

INVESTIGATOR: "Do they get to see you very often?"

PATIENT: "Yes, one was up here today."

INVESTIGATOR: "The young girl I saw?"

PATIENT: "Yes. The middle grandchild. She comes down to clean house for me. She's learning how to cook now. They're real good to me."

INVESTIGATOR: "I know that means a lot."

PATIENT: "Yes, it does."

INVESTIGATOR: "Which member of your family visits you the most?"

PATIENT: "My husband; he comes every day."

INVESTIGATOR: "Tell me more about how you sleep at night."

PATIENT: "I sleep real good at night and always have."

INVESTIGATOR: "Have you ever thought of yourself as a nervous person?"

PATIENT: "No. Just until recently and that kinda gets me down because I don't like to feel like that. No, I've never been the nervous type."

INVESTIGATOR: "Do you ever get down in the dumps or get the blues?"

PATIENT: "No, not until recently--just the last time that I've been here."

INVESTIGATOR: "Are you down in the dumps now?"

PATIENT: "Yes."

INVESTIGATOR: "Have you ever thought you might get so blue that you might take your own life?"

PATIENT: "No, Ma'am! (very emphatically) I love life too well. I'm going to hang on as long as I can."

INVESTIGATOR: "Mrs. A., what is your religious preference?"

PATIENT: "Baptist."

INVESTIGATOR: "Has your minister been to see you, or any of the chaplains?"

PATIENT: "Well, we've moved so much I don't really belong to any church. I was telling them (pointed to other patients in the room) that I'd like to go to church have them (the congregation) sing some of those old-fashioned hymns. The ones now--you don't even know them. You can't understand these new songs."

INVESTIGATOR: "You like the kind of music you could pat your feet to?"

PATIENT: "Holler!" I used to like to get in there and sing as loud as the rest of them."

INVESTIGATOR: "Mrs. A., what else can you tell me about how you feel about your illness. You said you didn't want to know what was wrong with you because you'd worry more if you knew what was wrong with you. Is there anything else you can tell me about your illness? What do you think about during the day?"

PATIENT: "I don't think too much about it (her condition) and I haven't thought too much about it all along. I do feel like I'd like to be able to get out and around more than I do and do the things at home I'd like to do, and I'd love to go shopping again, but I can't do that--but she (Dr. M.) did get me up to where I could one time, so I guess she's going to do it again."

INVESTIGATOR: "I see you're in a room with other patients. Do you prefer to be with others?"

PATIENT: "Yes, Ma'am!" (emphatically)

INVESTIGATOR: "Could you tell me why?"

PATIENT: "Well, when you're by yourself you just lay there and think. When others are in the room you're concerned with them and it's much more company. I never did want a private room and you know it's not bad being in a room with four beds, because you could be in a two-bed room and have someone in there who would drive you nuts; then you'd be stuck. But when you're in a four-bed room, there's so much going on. But when I've been in one before I've never had any trouble with any of them."

INVESTIGATOR: "Mrs. A., I want to ask you one more question about how you feel. You said you hadn't talked with your husband about how you feel--have you talked with anyone about how you feel about your illness?"

PATIENT: (Patient began to frown and worried expression reappeared.) "No."

INVESTIGATOR: "Could you?"

PATIENT: "No."

INVESTIGATOR: "You're talking with me about it--is it because. . ."

PATIENT: "I just don't want to worry them."

INVESTIGATOR: "You're trying to spare their feelings aren't you?"

PATIENT: "That's the way it is." (Patient is tearful again.)

INVESTIGATOR: "Do you think you could talk to nurses more about the things we've talked about if you had the opportunity?"

PATIENT: "I probably could because the nurse is not my family. I know they're here to help me, but I just don't want to put any more on my family."

INVESTIGATOR: "I think you're mighty brave, but I think your family could help you more than they already are if you would let them."

PATIENT: "Well, I just don't feel like I wanted to. My daughter-in-law is good as gold. She's had a nervous breakdown; she was out at W. for a right good while. She doesn't like hospitals. She was up here today, but I'd rather she didn't come because I know it upsets her. But my granddaughters and son have been here. And my husband comes every day."

INVESTIGATOR: "You have a real close family, don't you?"

PATIENT: "Yes, I do."

INVESTIGATOR: "That means a lot."

PATIENT: "In fact, I just moved closer to them. I was living a good ways from them. My granddaughters used to take turns coming over to see me. This house became vacant just down the street from them, not even a block away. So we moved closer to them and now they can come in more often. This middle one comes and she gets back in the kitchen and cooks and I tell her what to do. Her daddy told her the other day that she was getting to be a good cook and she said, 'I should because my Granny taught me.'"

INVESTIGATOR: "I bet you are a good cook, too."

PATIENT: "I've been doing it all my life."

INVESTIGATOR: "Mrs. A., has it been hard for you to talk to me now?"

PATIENT: "No, it hasn't; I've enjoyed it."

INVESTIGATOR: "Do you think it's helped you in any way at all? It's helped me immensely."

PATIENT: "Well, I'm glad I've helped you. I think you've helped me some, especially when you send those girls (nursing students) in to help me."

INVESTIGATOR: "I'd like to come back to talk with you later on. There might be some other things you might have to tell me--or some suggestions."

PATIENT: "You come back any time; I'll be happy to talk with you."

INVESTIGATOR: "I'm not trying to invade your privacy in any way. Everything you've told me is confidential, so don't worry about that."

PATIENT: "I don't mind talking about myself, but like I said, I don't want to talk with mine."

INVESTIGATOR: "I certainly understand and I'll see you soon. I hope you're feeling better. You are feeling better than you did yesterday, aren't you?"

PATIENT: "I felt terrible yesterday. I think I turned over and got the covers off me and caught cold and I could hardly move because it (congestion) was all in here (pointed to her chest) yesterday, but today it's moved."

INVESTIGATOR: "What gives you the most trouble--is it your chest or back, or what?"

PATIENT: "Just everything, just everything. I have trouble with my legs and my right hip has been hurting. I have a walker at home, but I got to where I couldn't even do that because my right leg was hurting so bad I was afraid it would give away with me. I hadn't seen her (Dr. M.) for five weeks so when I got to hurting a lot more, I went back to see her."

INVESTIGATOR: "Where did you go to see her?"

PATIENT: "The tumor clinic. She's a doll."

INVESTIGATOR: "She thinks you're one, too."

APPENDIX H

Interview with Patient B

Patient B was lying in bed in a darkened room with the door closed, and he requested that it be kept that way. His voice was barely audible at times; however, he responded easily except when his spiritual needs were discussed. During this time, he became tearful. The patient began talking spontaneously as the investigator approached.

PATIENT: "Well, I have no complaints. The only complaint I have is getting my medicine at night. It takes about an hour and a half to get it. I call at 9:00 p.m. and it'll be 10-10:30 or 11:00 before I get it. But all of them (the nursing staff) have been nice to me. I have no complaints on that score."

INVESTIGATOR: "Is this medicine to help you sleep, Mr. B.?"

PATIENT: "I have to take about four or five tablets plus my sleeping pill which I'd like to have about 10:00 p.m., but I can't get it then. Beyond that I have no complaints."

INVESTIGATOR: "How long have you been here in the hospital?"

PATIENT: "Six weeks."

INVESTIGATOR: "Could you tell me how sick you are? What is wrong with you?"

PATIENT: "I have a cancer of the lungs and it's spread. They (the doctors) haven't told me but I know it has already spread to my head and my lymph glands.

INVESTIGATOR: "Mr. B., how do you know this if you haven't been told?"

PATIENT: "I know how it progresses and it started before I came in here."

INVESTIGATOR: "When did your illness begin?"

PATIENT: "January, 1969. They (his doctors) operated on me the 30th of January."

INVESTIGATOR: "Did they tell you what they found?"

PATIENT: "They found a cancer and took out part of my lung. He (his surgeon) told me at the time that he hoped he'd gotten it all but he wasn't sure."

INVESTIGATOR: "Are you glad that they told you? Or would you rather not know?"

PATIENT: "No one wants to know (that he has cancer), but I would rather know than not know." (There is a long pause after this remark.)

INVESTIGATOR: "Have you talked about this with members of your family? Do they understand how you feel?"

PATIENT: "The doctor told my wife and me both."

INVESTIGATOR: "Do you have much pain, Mr. B.?"

PATIENT: "In my neck and shoulders and sometimes in my chest, but not severe."

INVESTIGATOR: "How is it usually relieved? "

PATIENT: "By medication, I guess."

INVESTIGATOR: "How are you being treated now?" Are you getting any type of treatment to help you with this problem?"

PATIENT: "They're giving me medications and, of course, X-Ray."

INVESTIGATOR: "What is your religious preference, Mr. B.?"

PATIENT: "I'm Catholic."

INVESTIGATOR: "Does your priest come to see you regularly?"

PATIENT: "Someone comes every three-four days."

INVESTIGATOR: "Have you found his visits help you?"

PATIENT: "I enjoy his visits."

INVESTIGATOR: "Have you ever considered yourself to be a nervous person?"

PATIENT: "I have been."

INVESTIGATOR: "Do you have trouble sleeping at night?"

PATIENT: "Most nights."

INVESTIGATOR: "Could you tell me why? Are you worrying about anything?"

PATIENT: "I think about things during the day as well as at night."

INVESTIGATOR: "Do you get down in the dumps?"

PATIENT: "Not often--about once a week."

INVESTIGATOR: "Is there any particular time in which you seem to get this way?"

PATIENT: "Just any time."

INVESTIGATOR: "Have you ever been so down in the dumps or so blue that you thought you might take your own life?" (Patient becomes tearful at this point.)

PATIENT: "I believe I would if I could, but I'm afraid to."

INVESTIGATOR: "What are you afraid of?"

PATIENT: "Well, I know when we leave here, we're going somewhere and I I fear the pain of hell." (Patient is crying.)

INVESTIGATOR: "Do you feel like you'll go to hell? Have you talked with your priest about this?"

PATIENT: "No."

INVESTIGATOR: "Could you talk with him about this? I think it would help a lot if you did."

INVESTIGATOR: "When do you expect him to come again?"

PATIENT: "I don't know."

INVESTIGATOR: "I can see that this worries you a lot, and I'm sure it would help you if you talked with him (the priest). Mr. B., I see you're in a private room. Do you prefer to be in a room by yourself?"

PATIENT: "Yes, it's better I guess although I haven't too many objections to a room with other people."

INVESTIGATOR: "Do you get lonely in here by yourself?"

PATIENT: "No, but then again I like my company."

INVESTIGATOR: "Who comes to visit you the most?"

PATIENT: "My wife, every day."

INVESTIGATOR: "Does she work?"

PATIENT: "No."

INVESTIGATOR: "Do you have any children?"

PATIENT: "No, but two nieces are just like my children."

INVESTIGATOR: "Do they come to visit you often?"

PATIENT: "Yes; one just called me--she's sick with a virus so she can't come in."

INVESTIGATOR: "What gives you the most trouble, Mr. B.? Is there one particular thing that really bothers you?"

PATIENT: "I just can't eat. I don't have too much pain."

INVESTIGATOR: "Are you up very much?"

PATIENT: "Not at all except to get over there in the chair. I can't walk."

INVESTIGATOR: "Have you ever been to physical therapy?"

PATIENT: "No."

INVESTIGATOR: "What suggestions do you have for nurses that might help other patients like you?"

PATIENT: "I like to see them (nurses) because they're so pleasant. All except one that I've seen down here have been real pleasant."

INVESTIGATOR: "Do you get to see them as often as you'd like?"

PATIENT: "No, because every two days they're gone and someone else is on."

INVESTIGATOR: "Have you ever talked to them like you're talking to me now?"

PATIENT: "No."

INVESTIGATOR: "Do you think you could talk with them if you had the chance?"

PATIENT: "Maybe."

INVESTIGATOR: "Have you ever wanted to talk with someone like you're talking to me?"

PATIENT: "Yes.

INVESTIGATOR: "What has held you back?"

PATIENT: "Well, they (nurses) can't sit down and visit. I know they're working. They're not even allowed to sit down."

INVESTIGATOR: "Oh, yes, they're allowed to but either they don't have the time or they don't take the time to do that."

PATIENT: "I didn't think they were allowed to."

INVESTIGATOR: "Now they can, but at one time they couldn't--several years ago it was against the rules to sit down in a patient's room, but it's o.k. now."

(There is an interruption at this point when a nurse brings the patient his medications.)

INVESTIGATOR: "Mr. B., do you understand the reasons for all the different treatments you've had such as all the X-Rays and the different drugs?"

PATIENT: "The drugs are experimental, I know that, but what I've been taking up until yesterday hasn't done me any good. Now they (the doctors) have started me on something new. That gives you an idea of what kind of shape I'm in."

INVESTIGATOR: "Well, I'm sure they talked to you about these drugs before you were put on them. Didn't they tell you it was something new and they wanted to see how it worked for you and if this didn't work, they'd try something else?"

PATIENT: "Yes, that's right."

INVESTIGATOR: "Is there anything else you haven't understood about your illness?"

PATIENT: "I would like to know how long they really expect me to live."

INVESTIGATOR: "Mr. B., I don't think that they could ever decide that."

PATIENT: "They have an idea."

INVESTIGATOR: "Well, if they do, they'd be very reluctant to say anything because so many patients live a lot longer than the doctor thinks."

PATIENT: "They told my sister two years ago that she would live two months and if she had lived one more day, she would have lived two months."

INVESTIGATOR: "Well, even though they were accurate then, doctors are usually very reluctant to say anything like this. I think it worries the patient more."

PATIENT: "Well, I don't want to linger. If you're going to die, I'd like to go on and die."

INVESTIGATOR: "I understand. Do you want to be here or would you rather be at home?"

PATIENT: "I'd rather be here."

INVESTIGATOR: "Mr. B., I'll be coming back to see you. Thank you so much for your help."

PATIENT: "You're welcome and I'm glad you came. I enjoyed it."

APPENDIX I

Interview with Patient C

Patient C sat on the side of his bed during the interview. He answered questions easily. He seemed to be quite embarrassed several times when he had to stop talking to remove excessive drainage from his mouth and nose. The noise level was high. The curtains were pulled around the patient's bed to provide as much privacy as possible.

INVESTIGATOR: "How long have you been in the hospital?"

PATIENT: "I've been here a month and three days."

INVESTIGATOR: "When did your illness begin?"

PATIENT: "It was first detected in August of 1968 and I had an operation then and found out it was a malignant tumor."

INVESTIGATOR: "What type of operation did you have?"

PATIENT: "They (surgeons) went into the sinus below the right eye."

INVESTIGATOR: "What did they tell you as a result of this operation?"

PATIENT: "They said it was malignant and had a long talk with me. They wanted to know if I would like to try the cobalt treatments first and in doing so it would mean that I would lose the sight in my right eye, which I have done. I also lost the hearing in that ear, which they hadn't anticipated, but I did, and I understand now that I'm going to lose some of my teeth.

INVESTIGATOR: "Did you take the cobalt treatments?"

PATIENT: "Yes, I did. They stopped them after 65 treatments. Then they did some research and decided to give me ten extra ones and they did that, so altogether I'd say I have had about 75 treatments."

INVESTIGATOR: "How did they affect you, Mr. C.; did you get sick from them?"

PATIENT: "No, the only effects I actually had was a breaking out in my mouth which was painful and before meals I had to use a syrup gargle to ease the pain so I could eat, but other than that it was no more than taking a sunbath."

INVESTIGATOR: "What are you here for now?"

PATIENT: "I'm here now to be built back up. I'd gotten in a very run down condition due to the fact that I lost my appetite to a certain degree and I had to go on a liquid diet because I can't open my mouth to chew. I got in a run down condition and my doctor recommended that I come in to be built back up again."

INVESTIGATOR: "Was surgery ever discussed as a possibility in your case?"

PATIENT: "It was at one time and Dr. J. said that it would not be too much of an operation."

INVESTIGATOR: "But did he decide later that it might be too much for you?"

PATIENT: "As yet they (doctors) have not told me this. I'm still in the process of being built up so if they can, they will."

INVESTIGATOR: "How did you feel when they told you what your diagnosis was? Did you want to know or would you prefer not to know?"

PATIENT: "Yes, I did. At a younger age, I wouldn't have wanted to know but at an older age I did want to know."

INVESTIGATOR: "Tell me more about this. Why did you want to know?"

PATIENT: "For several reasons; mainly so I could cooperate with them the best I could as long as I was able. Also, there are several other reasons--you have to make certain preparations, and that's what I wanted to do."

INVESTIGATOR: "So you really do prefer to know what is going on?"

PATIENT: "Yes, I do."

INVESTIGATOR: "Have you been sleeping well at night?"

PATIENT: "I would sleep very good if it wasn't for the drainage which tends to choke me up and interfere with my breathing and I have to wake up to clear that up. Other than that, I would sleep fine."

INVESTIGATOR: "Does anything else worry you?"

PATIENT: "No. That (worries), thank goodness, I don't have."

INVESTIGATOR: "Have you ever thought of yourself as being a nervous person?"

PATIENT: "I've been that way all my life."

INVESTIGATOR: "Well, I wouldn't have suspected that. You give me the impression of being calm, cool and collected."

PATIENT: "I know it--I didn't know I could take it (his illness) either. Something has happened since I've been here."

INVESTIGATOR: "You mean you're more nervous now than you used to be?"

PATIENT: "Oh, no, I'm a lot calmer than I used to be."

INVESTIGATOR: "Do you get down in the dumps at all?"

PATIENT: "Well, sometimes, but I've been able to throw it off by doing something--reading, or listening to the radio or TV. As Dale Carnegie says you can't think of two things at once and that's the way I've been working it."

INVESTIGATOR: "It looks like you've handled it pretty well."

PATIENT: "Well, you have to."

INVESTIGATOR: "Have you ever gotten to the point where you thought you might kill yourself? Have you felt this badly?"

PATIENT: "Well, I'm going to tell you yes, I did at one time."

INVESTIGATOR: "When was this?"

PATIENT: "About three months ago."

INVESTIGATOR: "Were you here then?"

PATIENT: "No, I was at home and I did have the feeling that I might possibly go through it (suicide), but I've changed my course since I've been here."

INVESTIGATOR: "Could you tell me how long this feeling lasted?"

PATIENT: "Not too long with the help of my wife."

INVESTIGATOR: "Do you think you might ever feel this way again?"

PATIENT: "Oh, no."

INVESTIGATOR: "What is your religious preference?"

PATIENT: "I'm a Methodist."

INVESTIGATOR: "Does your minister or hospital chaplain come by to visit you often?"

PATIENT: "Mine doesn't, no, because I was not a faithful church worker,

but the church which my boys were raised up in, which was Baptist, and I helped them out with their ball games and Sunday School and the Baptist minister has been to see me quite a few times."

INVESTIGATOR: "Have you found his visits helpful?"

PATIENT: "Yes, the first one was very helpful. That's when the change was made that I told you about."

INVESTIGATOR: "Have you ever talked with anyone the way you're talking to me now?"

PATIENT: "Well, to the Baptist minister. We got quite confidential."

INVESTIGATOR: "Do you think it helps to talk, to get some of these feelings out?"

PATIENT: "Yes, we're not able to understand everything and things that were on my mind, that I couldn't answer and I asked him and got his advice and opinion and like I said, it made a big change."

INVESTIGATOR: "Is there anything which you fear?"

PATIENT: "Not any more after talking to him."

INVESTIGATOR: "Is there anything about your care which you would like to see changed?"

PATIENT: (There is a long pause here.) "I expect they're (nursing personnel) doing the best they can with what they have. It's hard to get help and I know they're doing the best they can."

INVESTIGATOR: "Does any one thing upset you?"

PATIENT: "A little slow in answering when you want pain pills. You might be asleep and your pain wakes you up and you want the medicine then but sometimes there's quite a delay."

INVESTIGATOR: "Do you have a lot of pain?"

PATIENT: "At times, but if I keep on those pills regularly I don't. It's always there but bearable."

INVESTIGATOR: "Is it usually relieved by pain medications?"

PATIENT: "No, it's never entirely relieved. It's like a headache--at times it's really bad and if you take your medicine you can feel it tapering off and that's what this does to a certain degree and that's as far as it goes--it's never all the way clear."

INVESTIGATOR: "Mr. C., who comes to visit you the most?"

PATIENT: "My wife, but I tell her not to because she has work to do; she works here at the hospital."

INVESTIGATOR: "Do your sons get by often?"

PATIENT: "Yes, they do. One can't get by too often because of his working conditions, but when you get on my sons I'm going to brag on them. (Patient's face brightens up.) I lost my first wife after we'd had the two boys. They were about twelve and eleven when I met my present wife and she had a son. We got married. I waited until he was old enough to decide if he wanted to change his name or not, and after a while he told me he did, so he was legally adopted. He shares in everything just like my boys do. There's never been any difficulty there; everything has worked out marvelously."

INVESTIGATOR: "Any grandchildren yet?"

PATIENT: "Yes, two, but to get back to my boys--they're just like brothers; I have one at the U. of R. and on the dean's list for three years, so you see I'm mighty proud of him. Then my youngest boy is going to VCU; he gets discouraged at times when he can't get the five A's like the other can. The oldest boy went to a trade school and he is now an electrical foreman for one of the firms in town. They've given me very little trouble."

INVESTIGATOR: "Are you getting tired of being in the hospital, Mr. C.?"

PATIENT: "Naturally I miss home, but I feel like in my condition this is the best place for me, and I just have to reconcile myself to it."

INVESTIGATOR: "How are you feeling now in comparison with when you first came in?"

PATIENT: "I can't see much difference."

INVESTIGATOR: "What are the doctors telling you?"

PATIENT: "Right now, I'm just leaving it up to them. Dr. M. is the doctor who determines this and right now she's on vacation and I don't think it right to ask the others what she's got in mind."

INVESTIGATOR: "Do you think she may make some changes when she comes back?"

PATIENT: "I really don't think so--I may be wrong."

INVESTIGATOR: "What seems to be giving you the most difficulty?"

PATIENT: "The average person wouldn't think that a tumor in the sinus could affect so many of your minutes of life; such as

breathing, talking, eating or almost anything you try to do; it's always there."

INVESTIGATOR: "What is always there?"

PATIENT: "This condition in my sinus which affects everything. Lots of times if you have an ailment in your hip or somewhere else in your body, you would be free to talk, or do things a normal person could do, but it's hard for me to do anything with this."

INVESTIGATOR: "You seem to have adjusted to this fairly well."

PATIENT: "Like I told you earlier, I've talked with my minister and we've straightened things out; I'm also an admirer of Billy Graham's and it all comes back to the fact that I've been born again. I feel like my sins are forgiven and I haven't got to worry."

INVESTIGATOR: "Is there anything else you'd like to tell me before I leave?"

PATIENT: "No, I don't think so--it's been very pleasant talking to you. You have beautiful eyes."

INVESTIGATOR: "Thank you, Mr. C. I've enjoyed talking to you, too, and I'd like to come back to see if you've thought of anything else or have any suggestions you'd like to share with me."

PATIENT: "Thank you. I've found out since the change was made that you see things differently from before. You have a different outlook as time goes on."

INVESTIGATOR: "Do you think it helps to talk about these things we've talked about or does it hurt?"

PATIENT: "No, I don't think it hurts at all; I feel like this should be done more often. That's what is wrong with the world today."

(Patient's wife enters room and interview is terminated.)

APPENDIX J

Interview with Patient D

Patient D was sitting on the side of his bed smoking a cigarette. The curtains were pulled to provide as much privacy as possible; however, the noise level was a problem. He seemed to have no difficulty speaking and questions were answered easily.

INVESTIGATOR: "How long have you been in the hospital?"

PATIENT: "Five weeks tomorrow."

INVESTIGATOR: "When did your illness begin?"

PATIENT: "Last September--a year ago."

INVESTIGATOR: "How sick are you, Mr. D.?"

PATIENT: "It's hard to really tell; most of my trouble is due to not being able to eat, or swallow food. You see, I have this tumor on the larynx and I took cobalt--38 treatments--I think, and I have the tumor no more, but it left my throat in this condition and instead of getting better, it seems to have gotten worse in the last six or seven months. In January after I had finished my treatments, I went for a check-up every Monday and I told the doctor there that I had a very sore throat on the left side and he said he thought there was a little infection there, but it was getting worse and every time I'd go I'd remind him of it, but he was more interested in his line of work. But I sometimes think that if he had listened to me earlier he could have put me on medications earlier--I wasn't on anything at all and of course during the treatments I lost about 30 pounds, which is fairly normal, I guess, but then I started to go down very fast and I've lost about 62 pounds. I normally weigh around 178 pounds or right around that and so it's my opinion that perhaps if I'd had medication back earlier. . .but Dr. J. did tell me at that time that it might be a year or a year and a half before the throat would clear up, but it's continued to get worse so that it's almost impossible to swallow certain foods. It's only soft foods that I do eat, like soup--which has to be strained, or pureed vegetables and very few kinds of meat can I eat at all.

INVESTIGATOR: "Mr. D., why are you here in the hospital now?"

PATIENT: "For medication. He (his physician) finally recommended Dr. M. to me so I had an interview with her and she checked me out and she thought it best I guess. I was going down so fast--I only weighed 114 pounds when I came in here."

INVESTIGATOR: "What do you weigh now?"

PATIENT: "Just about the same. I haven't gained. I asked one of the nurses, but they don't bother to weigh me any more. The other day, a nurse was in here with the scales and I asked to be weighed and she weighed me--I weighed 115¼ pounds then, so I have gained a little."

INVESTIGATOR: "When you found out that you had a tumor did they tell you whether it was malignant or not?"

PATIENT: "Yes. It was malignant. (Patient said this word without apparent difficulty.)

INVESTIGATOR: "Did you ask this or did they tell you?"

PATIENT: "I went to J.W. Hospital before that and I had this lump on my throat which I hadn't paid much attention to, but it dated back to the summer. I thought it was just one of those things which would go away, but suddenly, just before I went to the hospital, it grew, but no soreness to it, but it worried me so I went there and the surgeon performed a biopsy on it and found it was malignant so he recommended that I have these cobalt treatments; then he would operate. Well, at the time I didn't know what the surgery involved. In fact, the doctor down where I was taking my treatments didn't know about the surgery either. He asked me one day if I was going to have surgery and I said "yes." So he called the surgeon and he said,"Yes, he intended to operate." I found out he intended to take my whole larynx and I refused because if I had been younger I might go along with it, but I thought I'd take my chances in preference to losing my voice entirely."

INVESTIGATOR: "How old are you?"

PATIENT: "I'm 69 years old."

INVESTIGATOR: "You said they told you it was malignant. Did you prefer to know this?"

PATIENT: "Oh, yes, I asked to be told. I don't think it's right not to. In lots of cases people are kept ignorant of the fact and everyone knows it except them. Of course, circumstances alter with different cases. I have a sister who lives in New Jersey who has a malignancy back of her eye. They didn't operate and advised her to take cobalt treatments. She's

been taking them about three weeks. I don't know whether they'll operate or not; I suspect it's too close to the brain. I don't know how she's stood it. She's getting symptoms now from the cobalt like I did but, of course, she hasn't had near as many as I did. No one ever really told her. I have a sister who lives here in R. We both thought she should know because she's a retired school teacher who lives alone in an apartment and she's 77 years old and she's always been the healthiest one, although she's the oldest of us three. It seemed to me that in a case like that she should know because she'd probably give up her apartment and make different arrangements."

INVESTIGATOR: "Did you tell her about this?"

PATIENT: "No, we didn't; I think she suspects, but at the time the doctors didn't tell her.

INVESTIGATOR: "How did you feel when you found out about your illness?"

PATIENT: "Well, I guess I took it in stride; it's just one of those things."

INVESTIGATOR: "Do you and your family live here in Richmond?"

PATIENT: "No, I'm not from Richmond and I have no family. I live alone in a small apartment. I live alone, but I have a sister here, but she has her troubles. Her husband suffered a stroke about a year ago." (Patient appears uneasy when discussing family status.)

INVESTIGATOR: "Mr. D., how long have you been coming here?"

PATIENT: "Well, it's been three months, but I can't see any improvement."

INVESTIGATOR: "What are you getting here?"

PATIENT: "I don't know exactly what the medicine is. At the present time, I'm getting very little for the simple reason that the medicines I was on dropped my blood count. They wanted to get that back up. Dr. M. said she wanted to continue the shots though because I have difficulty swallowing pills."

INVESTIGATOR: "Do you prefer to be in a private room or with other patients?"

PATIENT: "I wouldn't want a private room; I wouldn't mind being with only two, but we all get along. We're in the same boat."

INVESTIGATOR: "Why do you not prefer a private room?"

PATIENT: "Well, when I came I didn't expect to stay this long and you need company. But I've seen twelve come and go since

I've been here. Unless you're very ill. . .of course, I do suffer a lot of pain, especially at night. It starts in my throat and goes through my ear and top of my head."

INVESTIGATOR: "Is the pain mostly at night?"

PATIENT: "Yes, but I get a pain pill which sometimes stops it in a half hour, but I used to take them all through the day, too, so it's not as bad as it was."

INVESTIGATOR: "If it wasn't for the pain, would you sleep all right at night?"

PATIENT: "Well, of course, I take a sleeping pill at night, but no, I wouldn't sleep without that because there's too much commotion around here."

INVESTIGATOR: "Do you worry about anything?"

PATIENT: "Not particularly. I'm not what you'd call a worry-wart, but we all worry some, but I don't think I worry too much. I do worry about my sisters, but not myself."

INVESTIGATOR: "Do you ever get down in the dumps?"

PATIENT: "Oh, yes; I guess we all do; it wouldn't be human nature if we didn't. Yes, I have my good days and bad days."

INVESTIGATOR: "Have you ever gotten to the point where you were so down in the dumps that you contemplated suicide?"

PATIENT: "I have, yes."

INVESTIGATOR: "Has this been recently?"

PATIENT: "Yes, within the last year, but it passed away. It was just one of those things. That's not the answer I know."

INVESTIGATOR: "What is your religious preference?"

PATIENT: "I'm Protestant--Presbyterian."

INVESTIGATOR: "Has your minister been to see you; any of the hospital chaplains?"

PATIENT: "No, but my sister's minister from S.G. has been here, but I was taking a bath; I didn't see him, but he left his card. I don't know him very well; I have met him. I haven't been to church since I've been in Richmond."

INVESTIGATOR: "What do you as a patient see as your greatest need?"

PATIENT: "Well, that's difficult to answer. We all come here for health, or perhaps a cure, but I couldn't really say what was my greatest need."

INVESTIGATOR: "Do you think there's anything lacking in your care?"

PATIENT: "No, just petty things I guess."

INVESTIGATOR: "Like what?"

PATIENT: "Well, when you call for a pain pill and it takes 30 to 35 minutes to get here--you don't anticipate that pain--you usually have it before you ask for the pill. But those are minor things."

INVESTIGATOR: "Anything else?"

PATIENT: "No, except I don't go for the food, but even if I could eat, I don't think I'd enjoy the food too much."

INVESTIGATOR: "Are you on a soft diet or liquid diet?"

PATIENT: "Well, I choose my own now. I had to wrangle that out with the kitchen. It was a relief to get that straightened out. They (dietary personnel) were choosing my food for me. I said I could eat anything I could get down, so I should choose like the regular diet patients did. But it's getting worse. Everything sticks in my throat. I cough until I'm weak; then you don't feel like eating anything."

INVESTIGATOR: "Mr. D., have you ever talked to your family about your illness like you've talked to me?"

PATIENT: "I have with my sister here. My other sister I haven't seen since last January."

INVESTIGATOR: "Do you think it helps to share these feelings?"

PATIENT: "Oh, yes, very much. My sister here and I have always been close. Yes, I think it helps quite a bit."

INVESTIGATOR: "Do you think you could talk with other nurses about things like this?"

PATIENT: "Well, I don't know--if they were interested I could."

INVESTIGATOR: "Is there anything you'd like to ask me?"

PATIENT: "No, not that I can think of. Overall, I think I'm getting very good care here, although I'm not seeing any improvement. As I said, I think I'm getting worse."

INVESTIGATOR: "What did your doctor tell you about how you're getting along?"

PATIENT: "Well, she (Dr. M.) hasn't told me very much, but I don't see her too often. I've had so many other doctors over here who only stay about a month; now there's a new bunch so I don't get to know them very well."

INVESTIGATOR: "Prior to coming to the hospital had you been coming to the tumor clinic here?"

PATIENT: "No, I came directly to the hospital. I was only in the JWH three days. My surgeon there recommended these treatments. Of course, I didn't realize the after effects of the cobalt. The X-Rays since I've been here have shown that the opening where I swallow is smaller than it was."

INVESTIGATOR: "Do you have any trouble breathing?"

PATIENT: "Yes, at times I get short of breath, mostly at night. It might be the sleeping pill. For the last eight to nine months I've been associating pain with food; maybe it's all psychological. You figure everytime you swallow it's going to hurt you."

INVESTIGATOR: "Is there anything nurses could do to make you more comfortable?"

PATIENT: "Well, no--offhand I can't think of anything, only little things."

INVESTIGATOR: "If you could think of those little things, I'd like to come back by to talk to you about them."

PATIENT: "Well, all in all, I doubt if I can think of anything. I've been happy with my treatment here. Of course, the results are still there and if I left here now, I'd have to go to a nursing home. I couldn't care for myself. I don't know what the answer is. I was hoping this medication would be the answer, but so far, it hasn't been."

APPENDIX K

Interview with Patient E

Patient E was lying in bed when the investigator entered her room. She had just finished eating lunch. The environment was quiet except for two interruptions. The patient was tearful and seemed to be uncomfortable on one occasion. Pain medication was requested and given.

INVESTIGATOR: "How old are you?"

PATIENT: "Twenty-three; I had a birthday last week. I celebrated it here in the hospital."

INVESTIGATOR: "How long have you been here in the hospital?"

PATIENT: "This time I've been here a little over a week."

INVESTIGATOR: "What brought you back?"

PATIENT: "The pain in my abdomen. My abdomen had gotten very distended."

INVESTIGATOR: "Is the pain confined to the abdominal region?"

PATIENT: "Not entirely, but that was most severe."

INVESTIGATOR: "Where else do you have pain?"

PATIENT: "Quite a bit of pain in my shoulders and in my hips at different times."

INVESTIGATOR: "Could you describe this pain?"

PATIENT: "Pain is hard to describe anyway, but the pain in my abdominal region was almost a stabbing pain."

INVESTIGATOR: "Was it constant or in one particular area of the abdomen?"

PATIENT: "Very constant and in the right side more than any other area."

INVESTIGATOR: "You came in then to see if you could get relief from this pain?"

PATIENT: "Yes, that's right."

INVESTIGATOR: "How long have you been sick?"

PATIENT: "Since June of 1968."

INVESTIGATOR: "What did you find out was wrong?

PATIENT: "The original trouble was a growth in the base of my abdomen. I could feel the mass. There was no pain at all associated with it. I could feel pressure, that was all, so naturally I was concerned, so I went to a doctor--this was when I was in college and he referred me to a surgeon immediately, and they operated then and found that I had a tumor in my left ovary and tube and both of them were removed. I seemed to get along fine. I recovered from the surgery beautifully and went back to school and I didn't have any other significant trouble until March of 1969. At that time, I discovered another mass in my neck. I had no real reason to believe it was associated with the other, but you always think about things like that. I went to my family physician at home and he referred me to a surgeon at U.H. and he did a biopsy of that and found out it was a dysgerminoma, which was the same kind of tumor I had had removed the year before."

INVESTIGATOR: "Was this malignant?"

PATIENT: "They described it to me as a low-grade malignancy or benign. That's the only reference any doctor has made to a malignancy."

INVESTIGATOR: "What were your feelings when you found this out?"

PATIENT: "My first feeling was just plain old fear because it was new to me and I didn't know what to expect; it was so sudden."

INVESTIGATOR: "Had there ever been anything like this in your family?"

PATIENT: "Nothing like this at all. I had just lost my mother a year before with a sudden heart attack. I had seen a lot of health problems but nothing like this. I had always considered myself the strong one, but anyway when they discovered the tumor in my neck the doctors there were tremendous as far as explaining it to me and they had a plan of treatment all mapped out before they even told me about it, and that just made me feel real good--like there were all kinds of possibilities of things they could do and they explained to me that because I had the tumor in the abdominal area, then in the neck, there was a good possibility that there was a transportation factor. . .something in between, so they didn't even consider any more surgery. They started radiation therapy."

INVESTIGATOR: "How did you tolerate this?"

PATIENT: "They started me with cobalt. First they treated the mass in my neck and it was amazing to me because within a couple of weeks I could actually feel where the mass had melted away. Because they thought there was something in between, they ran extensive tests and there were things they saw so they treated the whole trunk area over a period of three months. During that time, for the first couple of months, I just got along beautifully. I had graduated from school and I had some disappointments, of course--I was supposed to go to work; instead I went to the hospital. I was able to lead a fairly normal life. I lived at home with my father and sisters and went back and forth to the hospital every day. I even got a job there. I had worked there the summer before I went to school, so I worked some while I was taking the treatments and this was good therapy for me too. Toward the end of this course of treatments when they got into the abdominal region, my resistance had begun to wear down. . .my blood counts were down and I got pretty sick and had to be in the hospital awhile."

INVESTIGATOR: "Were the treatments stopped then?"

PATIENT: "For awhile they were but they didn't have to be stopped for a long enough period of time that they couldn't resume where they had left off, so they were able to finish the entire course that they had planned. This was in May of last year--1969--and, of course, I was really weak, but I felt pretty good. Nothing had given me any pain except things like the nausea, but no other symptoms. I was just weak. By August I was ready to go out job hunting again. I moved to Richmond and started working down here with an insurance company; in fact, I'm still in it, but it's just been delayed because of all these trips back and forth to the hospital."

INVESTIGATOR: "When you moved down here--was this when you noticed the pain?"

PATIENT: "It was after I moved down here that I began to have pain in my right hip and my doctor back in C. found a spot in my hip and this was treated with X-Ray. This was in October. Then in November, 1969, a place showed up somewhere else--I can't remember now where they all were, but I recovered from that and went back to work. Then in December I got really sick. It just seemed like all these things came together at one time and I was in and out of the hospital in C. for about four months."

INVESTIGATOR: "When were you referred here?"

PATIENT: "I was ready to go back to work in March of 1970, but I was at the point where I still had to go back once a week for blood counts and routine check-ups because by that time, I was on chemotherapy and they (the doctors in C.) referred

me to Dr. R. here. There was a little transition period where they worked closely together and gradually all my records got shifted down here. Since I've had that done--well, I guess it was this past May that I started having trouble again and they gave me a two-week course of radiation down here and, of course, they've been working with the chemotherapy all along, and I've gone through at least three or four different drugs."

INVESTIGATOR: "Do you understand the reasons for all the different types of treatments you've had? Has all this been explained to you?"

PATIENT: "Not in great detail, but in all the detail that I could probably manage."

INVESTIGATOR: "Then you have a fairly good understanding of what's involved?"

PATIENT: "I feel I have a fair understanding. If I knew any more details, it wouldn't mean anything to me, and if I knew any less, I'd feel like I was in the dark."

INVESTIGATOR: "Does your pain come and go? And is it worse at night than during the day?"

PATIENT: "Now I have a very slight pain. . .that varies, too. They seem to think what I'm going through now is the result of the last chemotherapy I've been on and the tumor is breaking down and that's causing the pain. This is most encouraging because this is the first time they've been able to explain any of the pains I've had that way."

INVESTIGATOR: "Do you sleep well at night?"

PATIENT: "There are times when I worry about things, whether I want to admit it or not."

INVESTIGATOR: "Do you get down in the dumps at times?"

PATIENT: "Oh, yes; there are times when I get pretty far down, but I find that if you look hard enough you can usually find something to bring you up right fast."

INVESTIGATOR: "During these past two years have you ever felt so down in the dumps that you thought you might take your own life?"

PATIENT: "No, I've never felt that far out."

INVESTIGATOR: "What is your religious preference?"

PATIENT: "I'm Baptist; I was born and raised a Baptist and all my family have very strong faith and I feel I do too, and that's been very important to me."

INVESTIGATOR: "Has your minister or any of the hospital chaplains been by to see you since you've been here?"

PATIENT: "Yes, the minister from my old country church has been. He's been just tremendous. He's stood by me; he's always been a good friend anyway, and he's been down quite a number of times to see me in Richmond."

INVESTIGATOR: "I bet that helps a lot."

PATIENT: "Oh, it does. It helps to know that someone is there."

INVESTIGATOR: "Do you prefer to be in a room by yourself or would you rather be with other patients?"

PATIENT: "That's a tough question. Normally, I would prefer a semi-private room I think, but it doesn't bother me being by myself. I feel I'm better off by myself rather than being with someone who is very, very ill. I've had that experience too and it can be depressing."

INVESTIGATOR: "You said the doctor told you that the tumor was a border-line malignancy or benign. Did you want to know this information or would you rather have not known?"

PATIENT: "I'd rather know because having experienced it myself I have a different outlook on it than I thought I would have. I didn't think I would want to know either, but I want to know what's going on. It helps you to understand. I think you would be giving some type of false sense of security if you were mislead about something major like that."

INVESTIGATOR: "Have you told your doctor this?"

PATIENT: "They presented it to me like this, 'We assume this is what you want; is this true?' It definitely was. I feel I've been so lucky with all my doctors at C. and here. They seem to be master psychologists as well as medical doctors."

INVESTIGATOR: "Have you talked with anyone in your family about how you feel about your illness?"

PATIENT: "Yes, with my sister who's closest to me in age; she really is closest to me in all ways and I suppose I've shared more of my feelings with her than with anyone."

INVESTIGATOR: "Does your family get down to see you often?"

PATIENT: "Oh, yes; I see a lot of my family. Some of them are here every week if I'm not up there."

INVESTIGATOR: "Who visits you the most?"

PATIENT: "My sister who lives here in Richmond visits me the most. I have one very close male friend with whom I've been able to

discuss important things."

INVESTIGATOR: "What do you see as something nurses could do to help you that perhaps has not been done?"

PATIENT: "It would be hard for me to think of something they haven't done. I've been so pleased with the kind of attention I've gotten around here. I think one of the most important things the nurses can do is to let you realize that they understand the problems you're having. I think the worst thing that could happen, and I've never had this happen, but it would be one of the worst things, and that would be for them to show any kind of pity. They just have to make you feel kind of independent--to do things for yourself."

INVESTIGATOR: "Has it been hard for you to talk with me?"

PATIENT: "No, it hasn't been."

INVESTIGATOR: "Do you think it helps to get these feelings out, or is it difficult to express yourself?"

PATIENT: "It's always difficult to put this kind of feelings into words, for me anyway, but I think it's important we try to do it every now and then. I feel this has been very good for me."

APPENDIX L

Interview with Patient F

Patient F was lying in bed receiving intravenous fluids. Her speech was slow but coherent.

INVESTIGATOR: "How long have you been sick, Mrs. F.?"

PATIENT: "Eight years."

INVESTIGATOR: "That would be 1962 then when your illness began. What did you find out was wrong with you then?"

PATIENT: "The glands in my groin were enlarged."

INVESTIGATOR: "And you came to the hospital for a biopsy. What did they (the doctors) tell you?"

PATIENT: "It was malignant."

INVESTIGATOR: "After this diagnosis was made, what type of treatments did you have?"

PATIENT: "They put me on prednisone."

INVESTIGATOR: "Did this help a lot?"

PATIENT: "Yes."

INVESTIGATOR: "Have you been getting along well until recently?"

PATIENT: "I've been coming to the clinic for six years. Dr. M. has been attending me for six years."

INVESTIGATOR: "How did you react when you found out this was malignant?"

PATIENT: "I don't know."

INVESTIGATOR: "Were you surprised or did you suspect that it might be malignant?"

PATIENT: "I suspected it might be."

INVESTIGATOR: "Would you want to know that you had a malignancy or would you rather not know? Did you want the doctors to tell you what was wrong?"

PATIENT: "I guess I was a little scared."

INVESTIGATOR: "But would you prefer to know or would you rather they didn't tell you?"

PATIENT: "I guess it's better that I know."

INVESTIGATOR: "Why do you feel this way--why do you think it is better that you know?"

PATIENT: "I don't know."

INVESTIGATOR: "Do you have a lot of pain?"

PATIENT: "No, not so much now."

INVESTIGATOR: "Where is your pain?"

PATIENT: "I still hurt some in my breast and across my head, but it is better."

INVESTIGATOR: "How is it usually relieved?"

PATIENT: "They (nurses) give me something--usually needles."

INVESTIGATOR: "Do you sleep pretty good at night?"

PATIENT: "I do now. When I first came here I had so many doctors and nurses--they were coming in and out so often--then as I had a malignancy. I guess I'd rather not know."

INVESTIGATOR: "Then are you sorry they told you?"

PATIENT: "No, I guess not now."

INVESTIGATOR: "During this period of eight years that you've had this illness, have you gotten down in the dumps, or real depressed about this?"

PATIENT: "No."

INVESTIGATOR: "Has anything been worrying you?"

PATIENT: "No, I don't think so."

INVESTIGATOR: "Then you haven't gotten to the point where you were so down in the dumps that you thought you might take your own life?"

PATIENT: "Oh, no. I've never had any thoughts of that."

INVESTIGATOR: "Have you talked with members of your family about your illness?"

PATIENT: "Yes."

INVESTIGATOR: "Any one particular relative?"

PATIENT: "No."

INVESTIGATOR: "Do you have any children?"

PATIENT: "Yes, four."

INVESTIGATOR: "Do any of them live near you?"

PATIENT: "Yes."

INVESTIGATOR: "What is your religious preference?"

PATIENT: "Seventh-Day Adventist."

INVESTIGATOR: "Has your minister from home been coming to see you?"

PATIENT: "He's been once. You know he lives in K."

INVESTIGATOR: "Have your religious convictions helped you during your illness?"

PATIENT: "Yes."

INVESTIGATOR: "Do you think that if you had not been a religious person that things might have been different for you?"

PATIENT: "I don't know how they would have been. I don't think so."

INVESTIGATOR: "Have any of the chaplains here been by to see you?"

PATIENT: "No."

INVESTIGATOR: "Then I'll ask one to come by to see you. Could you suggest anything that nurses could do for you, or could do differently that might help you feel better?"

PATIENT: "I don't know anything. Dr. M. is a wonderful doctor and I know she is doing all she can."

INVESTIGATOR: "Do you have any questions about your illness that you don't understand?"

PATIENT: "No."

INVESTIGATOR: "I see you're in a room with another patient. Would you prefer to be in a room by yourself or with someone else?"

PATIENT: "At this time I would rather be alone."

INVESTIGATOR: "Could you tell me why, Mrs. F.?"

PATIENT: "I haven't been so well."

INVESTIGATOR: "Do you feel differently this time than you did the last time you were here?"

PATIENT: "It hasn't been long ago since I spent four days here."

INVESTIGATOR: "Do you feel different this time?"

PATIENT: "In many ways I do. I can't talk as good and I didn't have this swelling in my arm." I came in for a check-up and I had a high fever and I blacked out. Then they (the doctors) had to hospitalize me."

INVESTIGATOR: "I'm glad you can sleep well at night. That helps a lot."

PATIENT: "Yes, it does."

INVESTIGATOR: "So there's nothing that you can think of that nurses could do for you that's not being done for you?"

PATIENT: "I can't think of anything. I'm sure this is a research place."

INVESTIGATOR: "In some respects, yes. They're tying to find which drug, which medication, they can give you and which you can tolerate the best and help you with your disease?"

PATIENT: "That's good to know."

INVESTIGATOR: "Some of these medications are quite strong and have a lot of side effects so you have to be watched carefully to be sure that nothing happens that shouldn't happen."

PATIENT: "I'm sure they're learning all the time."

INVESTIGATOR: "Does this worry you or make you feel badly?"

PATIENT: "No, anything that will help me I'm glad for."

INVESTIGATOR: "Has it been hard for you to talk to me, or to answer these questions?"

PATIENT: "No more than anybody else."

INVESTIGATOR: "Do you think it helps to get these feelings out?"

PATIENT: "I imagine so."

INVESTIGATOR: "Have you thought about any of these questions before?"

PATIENT: "No."

INVESTIGATOR: "I've enjoyed talking to you and would like to come back by to see how you're doing and say hello."

INVESTIGATOR: "If there are answers you've given me which you'd like to change, or anything that's different, try to remember it so when I come back you can tell me. It would help a lot."

PATIENT: "You do that anytime, but I don't know what I'd change."

INVESTIGATOR: "The head nurse says that you've been a mighty good patient."

PATIENT: "And they've been good nurses."

APPENDIX M

Interview with Patient G

Patient G was lying in bed reading the newspaper when I approached. This he quickly put down as he spoke to me. An intravenous infusion was being administered in his left arm. Although the patient had private duty nurses around the clock, the day nurse was at lunch during the interview. There were no interruptions and the environmental noises were minimal.

INVESTIGATOR: "Mr. G., would you tell me how old you are?"

PATIENT: "I'm 64; I was 64 the first day of August."

INVESTIGATOR: "How long have you been sick?"

PATIENT: "I'd say my illness goes back five years."

INVESTIGATOR: "What did you find out five years ago? What seemed to be wrong?"

PATIENT: "I began by feeling giddy--dizzy, stepping on people's feet in a crowd and such things as that, and also my neck--it looked like I couldn't turn. I put up with it a long time and my doctor sent me to H, and at H, they (doctors) gave me a thorough going over, and in this check they did a procto-scopic and found something there that looked suspicious, so they took a biopsy and found that there was a malignancy there. That was in 1966 and, of course, they said it had gone right far and that surgery was required as soon as they could prepare me for the operation, so in March, '66, they removed eighteen inches of my colon at H. and I got along fine. I stayed there two months and got along fine except they couldn't control my temperature. Well, it finally got to where it was safe for me to go home, so I went home and was back at work with the Department of Agriculture in June, and for the next three years, I'd say I felt fine."

INVESTIGATOR: "Did you have any symptoms of any kind?"

PATIENT: "No, no symptoms of any kind. I'd go back to my surgeon in Baltimore every six months. Then last September I began to have severe burnings and pain in and around the pelvic area--

where the operation had been, so I went back to my surgeon in Baltimore and he looked in there and said there was some scar tissues which could account for the burning, but he didn't think further surgery was necessary, but I did suffer between that time and April when I went back again. I thought I might be going back for further surgery, but he examined me again and decided not to give me surgery. They made right much of a study and they decided at H. to put me on radiation for six weeks. That's when I told them that if I had to stay in the hospital for six weeks, just to take a five-minute treatment every day, why couldn't I transfer to Richmond and I'd only be 45 miles from home to Richmond, I could take the treatments there, so they finally got me transferred. It took about a month to get everything straight. They referred me to Dr. L. over here as the radiologist, and after he examined me for awhile, he referred me to Dr. M., the lady doctor, who specializes in chemotherapy. She put me on chemotherapy as an out-patient and I'd come over once a week for treatments. In the meantime, the temperatures were bothering me again and the therapy didn't seem to have much effect because of the temperature I was running. This had them puzzled, so finally she (Dr.M.) put me in the hospital to try to find the source of the temperatures. The first thing they did was try to find out if there was any kidney trouble, so she (Dr. M.) sent me to Dr. K., and he gave me a dye test and the dye would not enter the kidney from any source. So then he tried to get into that kidney with the needle to remove some fluid to see if there was any infection there; then he was going to remove the kidney because that might be the source of the temperature. After he couldn't get any fluid, because the kidney was inactive, of course, he found it wasn't the kidney so they they started making other explorations. They gave me an arteriogram to see if there was some source of infection around the pelvic area. I don't know what they found there, but anyway they gave me the proctoscopic again and sent me through Dr. L's department and they found a tightness in my colon in the vicinity of where I had been operated on before, so they finally performed the colostomy which did give me right much relief, and I've been able to get some relief since then. I'm not entirely out of pain and I don't guess I ever will be because there is a malignancy down below where they performed the colostomy, so that's what they're treating me for now with the chemotherapy."

INVESTIGATOR: "Mr. G., you sound like you're well informed as to what's going on; did you ask to be told all these things?"

PATIENT: "Yes, I asked."

INVESTIGATOR: "Then you preferred to know this rather than to be kept in the dark?"

PATIENT: "Oh, yes, I told the doctors I'm not afraid of the truth;

I want to know the truth. I've been just as contented here as can be. If I was home what could I do except stay in bed and maybe not have the facilities to meet the needs there? A couple of times since surgery I've had these temperature flare-ups, but I don't know what they found."

INVESTIGATOR: "In your own words, Mr. G., how sick do you think you are?"

PATIENT: "Well, I know it's a matter of time, Mrs. Turnage, because this business in the lower abdomen--they may be able to arrest it, but there's no cure for it, so I know my days are limited, but it doesn't bother me." (Patient is tearful.)

INVESTIGATOR: "You said you had pain--is this pain constant? Where is it?"

PATIENT: "Well, it's up in the rectum, mostly up there, the distal end is still there and I'm getting right much drainage. I was hoping it was an abscess that could be drained to relieve the tension down there. It's not near as bad as it was, but I know I'll never be relieved of it entirely."

INVESTIGATOR: "Do you have any pain in your back or elsewhere?"

PATIENT: "Oh, no."

INVESTIGATOR: "Are you up most of the time or in bed?"

PATIENT: "I'm in bed most of the time but I get up and walk the corridors about six times a day."

INVESTIGATOR: "Do you do this by yourself?"

PATIENT: "I can do it, but I have nurses with me all the time."

INVESTIGATOR: "I see you're in a private room, Mr. G. Do you prefer to be by yourself?"

PATIENT: "Oh, yes."

INVESTIGATOR: "Could you tell me why?"

PATIENT: "Well, in a semi-private room you never know who else they might bring in with you. It was my doctor's suggestion also that I go to a private room."

INVESTIGATOR: "You said your illness goes back five years. During this time have you ever gotten down in the dumps?"

PATIENT: "Yes, I was really down in the dumps after my operation in '66."

INVESTIGATOR: "Did you have trouble sleeping at night as a result?"

PATIENT: "Yes. Sometimes I wouldn't sleep a wink at night."

INVESTIGATOR: "Did you ever get to the point where you thought you might take your own life?"

PATIENT: "No, I never got that desperate. But I tell you, it (his condition) worried me. I'd worry about things that could never happen--I'd feel they were going to happen."

INVESTIGATOR: "How well do you sleep at night here?"

PATIENT: "I sleep very well here."

INVESTIGATOR: "Does anything worry you?"

PATIENT: "No, except the financial worries."

INVESTIGATOR: "Is your wife the one who visits you the most?"

PATIENT: "Yes."

INVESTIGATOR: "How many children do you have?"

PATIENT: "One daughter; no grandchildren."

INVESTIGATOR: "Would you say you were a closely knit family?"

PATIENT: "I should say so. My daughter means everything to me."

INVESTIGATOR: "Have you expressed these feelings to your family?"

PATIENT: "Yes, they know how I feel. And my wife doesn't want me to come home until I'm ready."

INVESTIGATOR: "What is your religious preference?"

PATIENT: "Well, I'm sort of peculiar--I'm Methodist but I go with my wife and daughter to the Baptist church."

INVESTIGATOR: "Has your minister been up to see you or any of the chaplains from MCV?"

PATIENT: "No, I haven't seen a chaplain, but it doesn't bother me because I have four ministers who come to see me--the two Baptist ministers, the Methodist minister and the Christian minister."

INVESTIGATOR: "It sounds like you're well taken care of in that department. Is there anything else you'd like to tell me?"

PATIENT: "I can't think of anything else, Mrs. Turnage."

INVESTIGATOR: "You said you've been sleeping all right at night?"

PATIENT: "Well, yes, but I never sleep more than four hours without waking up."

INVESTIGATOR: "How do you feel about being here in the hospital as far as nursing care?"

PATIENT: "Well, I have nurses around the clock."

INVESTIGATOR: "If there was anything that you could change in regards to your care, could you tell me what that would be?"

PATIENT: "Well, about the only complaint that I have would be about the transportation department."

INVESTIGATOR: "You mean you have difficulty going and coming from all the different tests?"

PATIENT: "Yes, in taking me there and then having to wait so long after you're through. It's only happened on two occasions."

INVESTIGATOR: "And you were in pain?"

PATIENT: "Yes, terrible pain and I had to wait two hours to get back."

INVESTIGATOR: "Does it disturb you to answer these questions?"

PATIENT: "Not a bit."

INVESTIGATOR: "I'm glad to know that you prefer to know what was going on."

PATIENT: "Yes, I told them (his doctors) in the very beginning I wanted to know. Of course, I knew when they put me on this (pointed to I.V. bottle) what it was for. That told me the story right there."

INVESTIGATOR: "Then you understand the reasons for all the tests you've had and the different medicines you're on. Is there anything you'd like to ask me?"

PATIENT: "No, I don't think so."

INVESTIGATOR: "Well, I've enjoyed talking to you and would like to come back to see if you've thought of anything else. Thank you very much."

APPENDIX N

Interview with Patient H

Patient H was sitting on the side of her bed which had the head elevated. She seemed to be apprehensive throughout the interview and began to cry when she acknowledged her previous intention of committing suicide when she had been depressed. There were no interruptions during the interview.

INVESTIGATOR: "First of all, Miss H, I'd like to ask you when did your illness begin?"

PATIENT: "My illness began in March of 1968."

INVESTIGATOR: "What did you find out at that time?"

PATIENT: "I discovered a lump in my left breast and had a mastectomy."

INVESTIGATOR: "What did your doctor tell you at this time?"

PATIENT: "They told me to follow this up with twenty-five cobalt treatments in order to get any cells that might have been dropped and which I did."

INVESTIGATOR: "And you were doing all right until when?"

PATIENT: "For about eighteen months. After the cobalt treatments I taught a year and never missed a day from school, but then in December of 1969, I had a second bout with it."

INVESTIGATOR: "What did you have done at that time?"

PATIENT: "I had the right breast removed, and incidentally, after the mastectomy in 1968 I followed that with a hysterectomy as a precautionary measure."

INVESTIGATOR: "What did all this mean to you?"

PATIENT: "Well, at first in March of 1968, I wasn't frightened so much; I was reassured that it had been gotten and would be taken care of, but in December of 1969, the story was a little different."

INVESTIGATOR: "How did you feel then?"

PATIENT: "Frightened and I've never felt that I would really stage a comeback."

INVESTIGATOR: "You did not feel that you would?"

PATIENT: "I did not. I felt that. . .I just never felt the same really and it could be because of my particular case rather than the general feeling of people who have experienced this."

INVESTIGATOR: "How do you feel now? How sick do you think you are at this point?"

PATIENT: "I'm afraid at this point the malignancy has gotten progressive because I look back and compare my strength now with what it was two or three months ago, and actually it is going progressively downward."

INVESTIGATOR: "What seems to be giving you the most trouble?"

PATIENT: "Now my breathing--I have difficulty with fluid accumulating around my lungs and in my abdominal region."

INVESTIGATOR: "Do you have much pain?"

PATIENT: "Periodically, but most of the time no."

INVESTIGATOR: "How is your pain usually relieved?"

PATIENT: "It's relieved by the tapping of the fluid and by pain medication, but the tapping is certainly the best."

INVESTIGATOR: "When did you have this done?"

PATIENT: "Yesterday, and I feel like a different person."

INVESTIGATOR: "You sound like you're well aware of what is going on; did you ask to know these things, or have you been told, or do you just suspect what these things mean?"

PATIENT: "I just suspect from observation of other patients of Dr.M.'s and in coming to her and talking with other patients, and my observation of the way they have felt and progressed compared with the way I feel."

INVESTIGATOR: "Do you feel that you prefer to know this or would you rather not?"

PATIENT: "I would prefer to know this."

INVESTIGATOR: "Could you tell me why?"

PATIENT: "Because I think it gives you a chance to better prepare for the future."

INVESTIGATOR: "So you'd rather not be kept in the dark?"

PATIENT: "That's right."

INVESTIGATOR: "You said you were a school teacher?"

PATIENT: "Yes, I taught mathematics for twenty-five years."

INVESTIGATOR: "How long has it been since you've taught?"

PATIENT: "I haven't taught since December of 1969."

INVESTIGATOR: "During your illness, which is now a little over two years, have you ever found yourself getting down in the dumps or depressed?"

PATIENT: "Yes."

INVESTIGATOR: "Did you find that you wanted to cry and could not, or were you able to get your feelings out?"

PATIENT: "Generally I could cry and generally if I could have about thirty minutes to myself I could cry and get it over with, then I could put up a good front and a lot of people, or most of my friends were not aware of this, but then I got to the point where I could not do this and I've had to get on a tranquilizer--Valium."

INVESTIGATOR: "Do you feel that your feelings are coming out more and more all the time now or are you still trying to keep them in?"

PATIENT: "They are coming out more and more but I'm trying to keep them in, but sometimes I can't."

INVESTIGATOR: "Who would you say is probably closest to you in your family and have you talked about these feelings with anyone?"

PATIENT: "I've talked about it with a real close teacher friend; she's not a member of my family. Then I've talked about it with my sister-in-law, but not to any great extent."

INVESTIGATOR: "Why is it that you haven't talked about it with anyone in your family?"

PATIENT: "Because I feel like they know it as well as I but they're trying to keep it from me."

INVESTIGATOR: "You're not doing this just to spare their feelings, are you?"

PATIENT: "Well, perhaps to spare their feelings and so I won't get totally torn up."

INVESTIGATOR: "How well are you sleeping at night?"

PATIENT:	"Sleeping at night is one of my greatest problems."
INVESTIGATOR:	"What seems to be the matter?"
PATIENT:	"They just seem to be an eternity long and this breathing problem. . .when I lie down I feel like I'm going to choke . . .I have to get up immediately."
INVESTIGATOR:	"Do you sleep with your head up like it is now?"
PATIENT:	"I sleep with it on two pillows generally."
INVESTIGATOR:	"You said you had been down in the dumps. You may not like to answer this question, but have you ever felt that you might get to the point where you would attempt to take your own life?" (There was a long pause here and patient responded haltingly and became tearful.)
PATIENT:	"I would like to, but I don't have the courage."
INVESTIGATOR:	"What about your religious convictions; what have these meant to you during your illness?"
PATIENT:	"During my illness my religious convictions have fluctuated; I thought I was a very religious person and my church meant much to me, and I'm sure it still does but there are times when I can't seem to communicate."
INVESTIGATOR:	"Has your minister been coming here to see you or any of the chaplains?"
PATIENT:	"One of the chaplains has been dropping by and my minister happens to be from R., and he's been contacting me regularly, but he hasn't been here but that is no problem."
INVESTIGATOR:	"Has this (suicide) come out before, what you just told me? Have you mentioned this to any of your ministers before?"
PATIENT:	"No."
INVESTIGATOR:	"What seems to frighten you most, Miss H.?"
PATIENT:	"It's the fact of the prolonged suffering that my family, as well as myself, have to endure."
INVESTIGATOR:	"Is it fear of pain perhaps that's bothering you?"
PATIENT:	"The fear of pain and just a lingering illness from which you know there's not a return and I know the problems, not only financial, that arise with prolonged illness."
INVESTIGATOR:	"Well, you're not trying to tell me that you've given up hope, are you?"

PATIENT: "Sometimes I have, but then that hope returns or else you couldn't stand it."

INVESTIGATOR: "Do you understand the reasons for all the different tests which you've had and all the different medications you've been on? Has this always been clear to you?"

PATIENT: "Not totally. I feel that they (her doctors) may . . . I want them to experiment if it helps someone who follows me, but sometimes I don't understand why the side effects of the medicines are so terrific, so bothersome."

INVESTIGATOR: "Sometimes they are. These are very potent drugs and must be monitored or watched very carefully."

PATIENT: "I feel that if the side effects are going to be this bad, why bother; why bother to try except for the fact that it may help someone else."

INVESTIGATOR: "What side effects have you had?"

PATIENT: "I've suffered with nausea a great deal and diarrhea; nausea and diarrhea are the two which have bothered me the greatest."

INVESTIGATOR: "You're taking medicines to try to counteract these, aren't you?"

PATIENT: "Yes, that's right."

INVESTIGATOR: "I see that you're in a private room; do you prefer to be in a private room?"

PATIENT: "Yes, definitely, not just from a selfish point of view of having my privacy but I'm so uncomfortable that I realize when I'm uncomfortable that I would disturb anyone else who might be in the room with me."

INVESTIGATOR: "Then you wouldn't agree that misery loves company?"

PATIENT: "No, I would not." (Patient laughs.)

INVESTIGATOR: "What do you see as the greatest need for a patient in your situation?"

PATIENT: "The greatest need for a patient in my situation is the love and understanding of their friends and just the little deeds that mean so much, nothing big, just the little things."

INVESTIGATOR: "Could you give me an example of what you mean?"

PATIENT: "Oh, just for a friend to offer to do a backrub, if you've had to lie flat on your back for a long time; or to come in and offer to do an errand to the grocery store or drugstore when you don't feel like picking up medicines. This is the type of thing I really appreciate."

INVESTIGATOR: "Have you had this type of friend?"

PATIENT: "Yes, I have. Some people think in terms of splashy flowers, which do brighten the room--don't misunderstand me, but I think these other little deeds and personal deeds mean more to me than some of the showier things."

INVESTIGATOR: "What do you see that nurses should be doing that perhaps they're not doing that could make you more comfortable?"

PATIENT: "I can't see that they could be doing anything better; they've been most cooperative with me. I've found total cooperation. In my weak moments and moments of despair when I was afraid that they would get disgusted with me, they've always appeared to have very much sympathy and they appear to want to help so I have no suggestions as far as nursing goes."

INVESTIGATOR: "If there was anything you could change in regards to your care, would you tell me what that one thing would be, or numerous things?"

PATIENT: "Well, the one thing, perhaps not related to change of my care, but it's in the understanding and that each day is different. You think tomorrow may be good but it's different, and I think you need this understanding."

INVESTIGATOR: "Tomorrow is not always what you'd like it to be?"

PATIENT: "Not like the day before, or even hours can be that way, and perhaps this is true with any illness but I've experienced it more with this one than with any others.

INVESTIGATOR: "Are you saying that you feel differently from day to day or from hour to hour?"

PATIENT: "Definitely."

INVESTIGATOR: "How about your disposition or attitudes?"

PATIENT: "My whole personality has changed; I guess because becoming weaker you have more time to think about these things and I hope it's not for the worst, but you do have so much time to think about spiritual things and why--the why of life; why am I here; where am I going."

INVESTIGATOR: "Have you ever talked this way before with any of the nurses or with your school teacher friend?"

PATIENT: "Yes, I have."

INVESTIGATOR: "Is it hard for you to do this?"

PATIENT: "I try not to do it often because I don't want to burden them with it; they would be glad to hear, but I don't do it often."

INVESTIGATOR: "You shouldn't feel like you're burdening them by talking this way. You know the Bible says "bear ye one another's burdens" and I think this is one way of showing that people do care and are concerned about you and they could help many times if they knew you felt this way."

PATIENT: "Then you think I should open up more often?"

INVESTIGATOR: "If you want to, I do. I just feel like sometimes it may be harder to keep it in than to let some of these feelings out."

PATIENT: "I sometimes keep it in, then I just have a sudden burst and that's when I empty it to my family, and then I try to halt before I get too involved."

INVESTIGATOR: "How often do they get down to see you?"

PATIENT: "They get down about every other day."

INVESTIGATOR: "How far away are they?"

PATIENT: "85 miles."

INVESTIGATOR: "Is there anything you'd like to ask me?"

PATIENT: "Well, in your experience have the things which you've asked me--have other patients in my situation felt the same way?"

INVESTIGATOR: "Definitely. They've expressed some of the same feelings and fears that you've told me."

PATIENT: "Well, I've wondered because you don't walk up to or talk to someone who is in a critical situation such as you did and ask them how they feel unless they wanted to express it."

INVESTIGATOR: "That's right. So far, I've only had one patient who refused to talk. I don't know what it was--I think perhaps she was denying the reality of her illness and if she had talked she wouldn't be able to control herself. I think this is how she may have felt."

PATIENT: "That's probably right. After I told you that I'd give you an interview, I wondered how I would hold up under it."

INVESTIGATOR: "Well, how do you think you've done?"

PATIENT: "I think I've done better than I thought because it's not easy to give way and talk about such things really and yet it's something we must face, and I hope I've been facing it bravely. My people say that I've been brave, but I'm afraid they don't know."

INVESTIGATOR: "Do you think talking like this has been helpful to you?"

PATIENT: "Yes, I do because I feel that if I'm not burdening or disturbing them I don't mind, but a family is so close to you and you know you're bound to become involved. This is the strongest that I've ever expressed myself to my family--I told them recently that unless I could get stronger, stronger enough to navigate on my own, that the quicker I could go, the better, but of course, that's not my choice."

INVESTIGATOR: "No, it isn't. But don't give up hope. I know Dr. M. is doing everything that can possibly be done to help you, and I'm sure she's told you that if this doesn't work, we have something else to try."

PATIENT: "I like her quotation--she says, 'There's much virtue in being as well as in doing.'"

INVESTIGATOR: "Well, I've enjoyed talking to you very much, and I'd like to come back tomorrow or the next day to see if you've thought of anything else to tell me. Some patients have made lists for me. Anything you can tell me would be deeply appreciated. Thank you very much."

APPENDIX O

Interview with Patient I

Patient I seemed apprehensive during the interview, which was done in the lounge on the floor. There were no interruptions during our conversation.

INVESTIGATOR: "When did your illness begin?"

PATIENT: "I had an operation in 1968 in November. Before then I had a spot on my back and a mole came in it. I came down here to Dr. L.'s office. He took it out and sent it away to California. It came back and it was a melanoma so he sent me right straight to the hospital over at S.H. and Dr. L. took it out. Then I went about two years and that place came back, so I went to him again and he sent me to Dr. M. in Petersburg. She wanted it taken out again, so he took it out again and sent it in. They were afraid he didn't get it all, so he went back in there inside of a week and took out a bigger place. Then I had a little node to come in this leg. I went to him and he took that out and that was melanoma, so he sent me to Drs. R. and M. and T. and L. Dr. T. and Dr. L. wanted to operate. They thought if they would take this out that would be the end of it, but it wasn't. It came over in this leg."

INVESTIGATOR: "Over in the opposite leg?"

PATIENT: "Yes; so that was in August of last year."

INVESTIGATOR: "So what did this mean to you? What did melanoma mean to you?"

PATIENT: "Well, it scared me; it made me real nervous."

INVESTIGATOR: "How sick do you feel you are, Mrs. I.?"

PATIENT: "Now?"

INVESTIGATOR: "Yes; how sick do you feel now?"

PATIENT: "Well, I haven't been sick until now, but I have been real sick for the last two months--haven't had any appetite. I've been so weak--had a nauseated feeling in my stomach."

INVESTIGATOR: "Do you understand the reasons for the different drugs or the different treatments you've been getting?"

PATIENT: "Well, they (her doctors) gave me that Finestrin the last thing before this and that just pulled my white count down so low and pulled my hemoglobin and everything down and that is when I started being sick. I came to Dr. M. and she told me. . .I'd go to South Hill and get checked at the hospital over there one week and over here the next and she told me they checked it over there four times because they didn't believe it (her blood count) could get that low and I could keep going. So she told me I was in the bottom of the barrel and she said that I just looked so good, and I told her that I felt as good as I had felt in my life. Then I went home and started to feeling bad."

INVESTIGATOR: "Have you had radiation or anything like that?"

PATIENT: "None whatsoever, but one minute over that little place over there on my knee. I had a little node to come there and Dr. T. took that out."

INVESTIGATOR: "So all of your treatment has been drugs primarily except for the biopsy and the surgery you had earlier?"

PATIENT: "Yes, Ma'am."

INVESTIGATOR: "Do you have much pain, Mrs. I.?"

PATIENT: "Nothing but gas."

INVESTIGATOR: "That's all?"

Patient: "That's all."

INVESTIGATOR: "No pains in your joints or anywhere...no aches or pains? Do you sleep pretty good at night?"

PATIENT: "I'd sleep good if it wasn't for that gas?"

INVESTIGATOR: "Where is this gas?"

PATIENT: "It is in that side. It won't go out; it'll go down there and just come back."

INVESTIGATOR: "Does anything worry you?"

PATIENT: "Nothing but my condition. You know that would worry anybody."

INVESTIGATOR: "Does it keep you awake at night?"

PATIENT: "No."

INVESTIGATOR: "Have you been able to talk to your family or any member of your family about how you feel about your illness?"

PATIENT: "Yes, Ma'am, yes, Ma'am."

INVESTIGATOR: "Anyone in particular, or all of them?"

PATIENT: "All of them."

INVESTIGATOR: "All of them. . . they all know?"

PATIENT: "Yes."

INVESTIGATOR: "How do you feel about your condition?"

PATIENT: "Well, I really don't know what you mean now?"

INVESTIGATOR: "Well, you said that you've been able to talk with them. What have you been telling them about your condition?"

PATIENT: "I just tell them like it is. . .they know."

INVESTIGATOR: "They know?"

PATIENT: "They know."

INVESTIGATOR: "Do you get down in the dumps, Mrs. I.?"

PATIENT: "Well, sometimes I am. I get lonesome."

INVESTIGATOR: "How do you control yourself when you get this way?"

PATIENT: "Well, Dr. M. gave me some nerve tablets--Valium, and I think they help me some and she gave me some pain pills to take when my side is hurting and they've helped me a whole lot."

INVESTIGATOR: "You've never gotten to the point where you've thought you might take your own life?"

PATIENT: "No, Ma'am, no Ma'am."

INVESTIGATOR: "Could I ask you what is your religious preference?"

PATIENT: "Christian."

INVESTIGATOR: "Has your minister been coming to see you?"

PATIENT: "Yes, Ma'am."

INVESTIGATOR: "Have you found his visits helpful?"

PATIENT: "Yes, they are. He's so encouraging."

INVESTIGATOR: "Do you have a lot of hope?"

PATIENT: "Yes, I do."

INVESTIGATOR: "That you're going to get over this. . .you're not going to give up, are you?"

PATIENT: "I've got hope that this is going to help me."

INVESTIGATOR: "How many children do you have?"

PATIENT: "Three."

INVESTIGATOR: "Are they all grown?"

PATIENT: "All grown, married and have children of their own."

INVESTIGATOR: "Do you get to see them very often?"

PATIENT: "Well, they're all right there at me. . .live right close to me."

INVESTIGATOR: "Is there anything you'd like to ask me? Anything about your care that you don't understand?"

PATIENT: "Not that I know of now."

INVESTIGATOR: "This is the first time that you've been in this hospital, isn't it?"

PATIENT: "It's the first time that I've been on this floor, but I was on the fourteenth floor two years ago when I had this operation on my leg. . .when they took the glands out of it."

INVESTIGATOR: "When they operated on you, did they tell you whether this was malignant or not? What did this mean to you?"

PATIENT: "They just told me it was a melanoma and I knew that was malignant."

INVESTIGATOR: "How did you know that?"

PATIENT: "Because I looked it up in the dictionary."

INVESTIGATOR: "Would you want to know this, Mrs. I., or would you rather not know that it was malignant?"

PATIENT: "Well, I just don't know which would be the best."

INVESTIGATOR: "But you never asked them though, you looked it up in the dictionary?"

PATIENT: "Yes."

INVESTIGATOR: "Some patients want to know and some don't want to know. Do you think it helps you to know?"

PATIENT: "Yes."

INVESTIGATOR: "Could you tell me how it helps you?"

PATIENT: "No, I cannot tell you how."

INVESTIGATOR: "But you'd still want to know?"

PATIENT: "Yes."

INVESTIGATOR: "Now I see that you are in a room with another patient. Do you prefer to be with others or would you rather be in a room by yourself if there was one available?"

PATIENT: "Well, as long as they're not real ill and they don't bother me. I like being in a room with somebody."

INVESTIGATOR: "Is someone in your family here most of the time?" (Patient's sister was visiting her before the interview.)

PATIENT: "Yes."

INVESTIGATOR: "I know that helps you a lot."

PATIENT: "Yes, it does."

INVESTIGATOR: "Is there anything you'd like to see changed in regards to your care, whether it be nursing care or doctors or anything; anything you'd like to see done differently?"

PATIENT: "Well, I never had anyone be any nicer to me. No one could be any nicer to me than they've been."

INVESTIGATOR: "Can you tell me what you think would be the greatest need for a patient in your condition?"

PATIENT: "The greatest need would be something to cure it."

INVESTIGATOR: "Can you think of anything else?"

PATIENT: "Well, trusting--putting your faith in God, I think. Because I think God works through the nurses and doctors. I feel that He does."

INVESTIGATOR: "Is there anything else that you can think of that would help me, as a nurse, to help other nurses in caring for patients like yourself?"

PATIENT: "No, I can't think of anything."

INVESTIGATOR: "Is there anything you don't understand about your treatments?"

PATIENT: "No, of course I don't know it all, but I'm just trusting in the Lord and the doctors that it will help me."

INVESTIGATOR: "Did they tell you how they hoped it would help you?"

PATIENT: "Yes. Dr. M. told that she had two men that it (chemotherapy) had just taken their nodes right on down and Dr. W. told me that I was just going to have to have patience, that it was going to take at least a month after I finished taking the treatments before I would see any decrease in the nodes."

INVESTIGATOR: "Have you noticed any side effects from the treatments that you've been getting?"

PATIENT: "I haven't so far."

INVESTIGATOR: "Well, good. How many treatments do you expect to get?"

PATIENT: "Ten. I told him that I just didn't have no appetite. It looked like my appetite wasn't getting any better. Now he told me today that I'd just have to have patience, that this treatment took a good while."

INVESTIGATOR: "You look like you're a pretty patient woman, are you?"

PATIENT: "I am."

INVESTIGATOR: "How old are you?"

PATIENT: "I'm 63."

INVESTIGATOR: "I think I've asked you everything I need to know. Is there anything else you'd like to add?"

PATIENT: "No."

INVESTIGATOR: "You've helped me a lot, Mrs. I, and I want to thank you for consenting to talk with me."

PATIENT: "I was glad to help you."

APPENDIX P

Interview with Patient J

The room was dark. There were no interruptions during the interview. The patient's husband was there but left when the interview began. The Patient seemed comfortable and at ease. She was sitting on the side of her bed.

INVESTIGATOR: "Mrs. J., when did your illness begin?"

PATIENT: "In May of 1968, but I'd had all these symptoms for six months before and my doctor at home had done X-Rays and everything, but they couldn't find anything and finally the surgeons said they would have to do an exploratory in the abdomen. It (the tumor) was sitting in the middle of the abdomen and attached to the colon. This didn't show up on X-ray or anything. As I came out of it (anesthesia) of course we had nurses around the clock and they were hired as terminal, no one said anything to me about it and finally I said to my husband, 'What did they find?' and he said, 'They sewed you back up.'"

INVESTIGATOR: "That's all he said?"

PATIENT: "Yes, that's all he said."

INVESTIGATOR: "What did this mean to you?"

PATIENT: "Dear, I've been with people with cancer for years. I do a lot of visiting the sick in hospitals for St. John's Episcopal Church and I've been with many people who had cancer, so I know the road. It didn't depress me. Maybe I'd had so much dope anyway, but it didn't at all, and after all we have to face these things and I said to my husband after he said they'd sewed me up, 'What are they going to do?' He said they were going to use cobalt. But it was a rocky road because I was allergic to so many of the drugs they tried, first one and then another. I think I was in there about two months, and I had RN's around the clock which were hired for terminal care."

INVESTIGATOR: "How do you know that they were hired for terminal care?"

PATIENT: "Because they told me. One of them said to me, maybe because I wasn't crying or gnashing my teeth and carrying on, because

I'm not of that temperament and I've seen enough of life to know that if I have cancer, I'll face it, and I think this is the only way a cancer patient can get along. Get straight with his God, right in the beginning and you know this is funny, but at home a number of ministers have asked me this question and I've said the only way is to put yourself in the hands of God. Nothing else makes any difference. But there I was in that little room with my people going and coming. My youngest son is a doctor and it seemed to me I could study their faces--nothing was ever said. I said to my son, "Son, don't be so depressed over this. It is not at what age you leave this world, but it is how you live the life that has been given you while you are here on this earth. He said, 'Yes, Mother.' But strangely, and I think this must have been unusual for the doctors, because the surgeon had to leave to go to the west coast to see his mother and he came to see me before he left and sat on my bed and said, Mrs. J., I'm not sure you understand what is wrong with you.' And I said, 'Why, certainly I know what is wrong with me.' Of course, it usually throws everybody into a tizzy when they find out they have cancer. I can live long enough to find somebody who can say cancer without being so scared that they don't know what they're doing, because they can go right out here on the street and get hit by a car and be gone in five minutes. I do think peace with yourself means a great deal, no matter what you have. I've had fine doctors and my family all around me and friends everywhere and I knew it--you could just feel it. It's not my will but Thine and for this reason this has been my attitude from the beginning and has always been. So far He has spared me. Sometimes I hope that I'm worthy of the sparing so I can do what He wants me to do."

INVESTIGATOR: "I think it's wonderful that you're still helping other people."

PATIENT: "As soon as I was stronger I got up. At first, I was addicted to the drug and that was difficult to come off, but I did."

INVESTIGATOR: "Your husband told me that you had done a lot of visiting and counseling with cancer patients. Could you tell me what you shared with them?"

PATIENT: "In our church we had a man who was a chemist and I didn't know at the time, but while I was ill he had cancer of the lung and they removed the lung. But I think somebody missed the boat there. He went home and became so depressed that they (his doctors) had to bring him back. Well, if somebody had taken the time to talk to him, things might have been different. My minister told me about it and he said he thought I could do more good for him than anyone else. I entered his room with a bright red coat on. . .I always wore bright colors after I left the hospital. He greeted me very

nicely. I talked to him along the lines of getting another attitude towards this. It is not hopeless. Many things have been done with cancer and they're doing everything to help you, now you do your part. You've got to want to live and fight to live. Now I'm not going to wear you out, but if you want me to come back to see you tomorrow, I'll be glad to and I made several trips back to see him. He lived about a year after that. I saw him at church regularly. I started counseling--I'm not an expert, nor do I claim to be an expert--but I've seen so many of them on my own about twelve years ago after the suggestion of our minister. You look at life and honestly--is there no dignity in death? You look at people's families come there and they're heart-broken, they're not allowed in the room. I told Dr. M. last night that this is one thing you doctors and nurses must learn; is that there is dignity in death and I think you're robbing your patients of this. Their loved ones want to see them. I think I would almost say to you and my husband and children to let me stay at home because they're going to keep me alive on glucose."

INVESTIGATOR: "You feel then that some measures to prolong life are un-dignified?"

PATIENT: "I do. I recently had a friend who had cancer for four years and he was at home, but he fell and his wife couldn't get help so they took him to the hospital and when she went to see him they were running tubes down him and he was so near death. Of course, they have to do it--this is very noble. Now the reason I'm here at MCV is because my son said no Bethesda, no Sloan-Kettering. I'm sending you to Dr. M., who will give you tender, loving care. This is a mistake that doctors make--there is a human side to it."

INVESTIGATOR: "What do you see as the greatest need for patients who are facing this?"

PATIENT: "When they're told that they have cancer, they need reassurance from their doctor or their nurse. Because many things have been accomplished with this. I wouldn't be here today if there weren't. But the fear of the word cancer is so great. If you can say it out loud from the very beginning, keep your faith and hope and get straight with your God. You need someone with compassion and understanding and a love of mankind. You know it's hard to believe this, but we had to get rid of the RN's and put on LPN's in order to get me off the drug because they were hired for terminal care and they were giving me hypodermics as soon as I came out of the operating room."

INVESTIGATOR: "Do you sleep all right at night?"

PATIENT: "Well, they give me all this stuff, but I think I would sleep without it. I had a hard time eating because the cobalt made me so sick, and I was getting so thin. That's when they said

you don't understand what's wrong with you, do you? And I said why of course I understand. This is it--I think that there must be more compassion and more understanding nurses. I know they're busy, but if they could just sense their patients and the same goes for the doctors.

INVESTIGATOR: "Do you prefer to be in a private or semi-private room?"

PATIENT: "I'd prefer to be in a private room. There are arguments for both sides. When I went in the second time, I was put in a semi-private room, and I was always afraid that I would disturb the patient in the room with me who had a broken spine. Another thing, my family was in and out and this was such a boost when you're in such a fix."

INVESTIGATOR: "You said you felt that patients should be told that they have cancer. Do you also feel that it helps to talk about it like we've been doing?"

PATIENT: "Yes, I think anytime you can get a cancer patient, and this may apply to patients with other diseases, too, to talk about it part of the fear leaves you."

INVESTIGATOR: "Have you shared your feelings with your family or with anyone else?"

PATIENT: "Oh, yes; they know exactly how I feel about everything."

INVESTIGATOR: "Mrs. J., you said the first nurses you had were hired for terminal care. How did you feel about this?"

PATIENT: "I knew I had it although no one had said it. When my husband told me they had sewed me back up and then from then on I knew. The nurses had the attitude that I was terminal and that they had to keep me comfortable. If I turned over in bed, they would give me something for pain, and I became addicted ant it was so hard to get off the drugs. I couldn't until I let them go."

INVESTIGATOR: "Do you see any way of giving hope to those who have lost hope?"

PATIENT: "If you can give them the idea that something can be done for cancer. It's not hopeless, look at me."