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A DELPHI STUDY TO DETERMINE METHODS TO AID

THE TERMINALLY ILL PATIENT AND

THEIR FAMILIES

By

LA NORA GREGORY BLOOM

Phillips University Enid, Oklahoma 1962

Master of Science Oklahoma State University Stillwater, Oklahoma 1973

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Thesis Approved:

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Graduate Cóllege

DEDICATION

I wish to dedicate this study to Burl Edwin Gregory, my father. Throughout his life, and as he died with cancer, he always lived the belief that all people are worthwhile and we as fellow human beings should take the time to listen, to help and be accepting. He also taught me that the quality of honesty and keeping one's word was truly the mark of success!

It is with love and respect that I make this dedication.

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iii

TABLE OF CONTENTS

Chapter	r	Page
Ι.	INTRODUCTION	1
	Statement of Problem	3
II.	SELECTED REVIEW OF LITERATURE	4
•	Introduction	4 10 15 23 26
III.	METHODOLOGY	27
	Introduction	27 27 30 32 33 34 34 35
IV.	PRESENTATION AND ANALYSIS OF THE DATA	37
	Introduction	37 37 38 46 50
۷.	FINDINGS, CONCLUSIONS, RECOMMENDATIONS	55
	Summary	55 56 57 58

iv

Chapter	Page
SELECTED BIBLIOGRAPHY	61
APPENDIX A	65
APPENDIX B	67
APPENDIX C	69
APPENDIX D	71
APPENDIX E	77
APPENDIX F	79
APPENDIX G	81

•

۷

•

LIST OF TABLES

	Page _.
Number and Percentages of Participant Returns	32
Statements of the Perceived Methods for the Terminally III	39
Statements of the Perceived Methods for the Family of the Terminally Ill	41
Overall Groups' Ranking of Top Ten Statements (Part A) Methods for Terminally Ill Patients	43
Overall Groups' Ranking of Top Ten Statements (Part B) Methods for Families	44
Variance and Chi Square Values for Part A	47
Variance and Chi Square for Part B	48
Computed Mean Variance for Each Individual Group Over Part A for the Patient and Part B for the Family	50
	<pre>Statements of the Perceived Methods for the Terminally III</pre>

.

vi

CHAPTER I

INTRODUCTION

All people must face death as they must face life. Yet, in our modern society, we have more than any other society avoided a direct approach to age and to dying by denying them in word, in fact, and above all in worth (Cutter, 1974). Like sex until the last decade, death has been unmentionable in what was known as "polite society." We "pass away," "go to our resting place," but we never die. Our whole society has tried to draw a curtain around the ultimate reality. The preparation for dying is left to the individual who behaves as though he were going to live forever (Dennison, 1972).

Every day more than 5,000 Americans die. Seventy-five percent of these are "processed out" of crowded institutions (Quint, 1967). All kinds of errors follow as we attempt to conceal death from ourselves, from society and from the dying, themselves. Sedation with drugs at the approach of death, if instituted for the sole purpose of preventing the dying person from dying consciously, is a regrettable practice (Crane, 1975 and Hunt, 1971).

By barring children under sixteen from most hospital terminal wards and often funerals, we shield them from the last look at the face of death and suffering (Mannes, 1973).

The dying patient is frequently in an intensive care unit with much bewildering equipment hooked into him, with his family in the

corridor and allowed entrance for short intervals only. Young children are seldom present. They are kept away even if the dying individual might wish them near. Perhaps a twelve-year-old child might disrupt hospital efficiency and is excluded for that reason. If so, it is a poor reason indeed. We try to hide, by not allowing visits or by avoiding visits to the chronically ill, whether they be young or old (Krant, 1974).

An intimate contact with death is never easy. People may not wish to die alone and out of sight and yet most of them do. The Center for Death Education Research at the University of Minnesota surveyed 560 hospital deaths and discovered that in most instances no family members were present at the bedside; that survivors generally learned about the dying through a phone call of some nurse or clerk (Shepard, 1975).

Professionals have stated the absence of family members is easier on the patient and the family members. Yet many questions have arisen concerning whether or not this is really true, or if it is being done for the convenience of the health care institutions (Sudnow, 1967). Often it becomes evident that survivors question over and over, in the months to come, if the loved one was alone, were the staff and doctors really doing all they could, or did the deceased call out for his family (Taves, 1974).

The lack of the familiarity with the subject of death and a fear of unknown elements contribute in large measure to the feelings of dread and indignity when death impinges. If society can understand and lose their terror, by study and familiarity, then the greater the likelihood that comfort and aid can be provided to family and friends

who face death, and the greater the probability that prople can survive their passing with less distress.

Statement of the Problem

In the State of Oklahoma, the number of fatalities for the year of 1975 was 27,165. Of these deaths, 24,854 were due to chronic disease. Chronic or terminal illness is one in which the illness is drawn out so that the individual and his family has a chance to reflect upon the eventual death (Bureau of Statistics, 1975). Often it is felt that chronic or terminal illness is a rare thing, but it now accounts for 90 percent of all the adult deaths in America every year (Cutter, 1974).

In dealing with dying and the death of the terminally ill, families and the patients, as well as personnel, there is need for a better understanding of what to expect and what methods would be most beneficial in aiding those involved to adjust and grow in acceptance of this crisis. At the community level, there is a need for more teaching and for more research into the care of the dying (Lamerton, 1973; Cronk, 1972; Shepard, 1975; and Kavanaugh, 1974).

In this study the researcher would like to find the answer to the following questions: What methods could best help the terminally ill patient and their families? What methods would (1) ministers (2) psychologists and psychiatrists (3) doctors and (4) survivors perceive to be the most helpful? How would a random sample of these populations rank these methods?

In finding results to these questions, this study should give patients, families and personnel a more concrete plan to begin to work so they might accept and enhance the lives of those involved.

CHAPTER II

SELECTED REVIEW OF LITERATURE

Introduction

The following review of literature is organized into four areas which would be considered to have the most likely affect on a terminal patient and their families. The first section reviews the various stages that the dying person may pass through as he strives toward acceptance of his death. Section two examines the emotional distress, or the indignities of dying as experienced by the terminally ill. The third section reviews the various suggestions of methods to help aid in emotional adjustment and the findings of the affect of certain treatments as they have been applied in care of the dying. The last section examines the families' reactions and methods of aiding families faced with the dying of a loved one.

Stages Associated With the Dying Patient

Little examination had been given to patterns of dying or the study of thanatology until 1969 when Kubler-Ross conducted her study on patients with terminal illnesses (Krant, 1974). Kubler-Ross has delineated five psychological stages in the process based on her work with terminally ill patients in a Chicago Hospital.

Her deep concern with their welfare is evident. Her book, <u>On</u> <u>Death and Dying</u>, is a clear manifestation of care for those who are

facing death. This study has done much to renew a humanistic approach to dying and encourage others to study thanatology. It stands as an antidote to some of the calloused, conventional hospital procedures surrounding the dying patient described by Sudnow in <u>Passing On</u> (1967) and by Glaser and Strauss in <u>Awareness of Dying</u> (1969).

Kubler-Ross (1969) interviewed dying patients who were asked to speak of their fears and hopes, dreams and nightmares. From these studies, she explicates five psychological stages of dying. The first stage is that of denial. Among the patients interviewed, most reacted to the awareness of a terminal illness at first with the statement, "No, not me, it cannot be true." This initial denial was true for patients who were told outright at the beginning of their illness as well as for those who were not told explicitly and who came to this conclusion on their own a little later on. Denial, at least part denial is used not only during the first stages of illness or following confrontation but also later from time to time. Patients seemed able to consider the possibility of their own death for a while but then have to put their consideration away in order to pursue life. When denial can no longer be maintained, it is replaced with the second stage, one of anger. This stage reveals feelings of rage, envy, and resentment. The next logical question becomes, "Why me?" During this stage, patients project their anger on everyone and everything about them. The problem here is that few people place themselves in the patient's position and wonder where this anger might come from instead of trying to understand and deal with it.

The third stage is the stage of bargaining, which lasts only for brief periods of time. Here the patient bargains with God or those

around him. "I'll do this if you'll let me live, or I'll do this if you'll give me a few days without pain."

When the terminally ill patient can no longer deny his illness, when he begins to have more symptoms or becomes weaker and thinner, he cannot smile it off anymore. He feels a great sense of loss, which leads to the fourth stage, the stage of depression. This stage contains two types of depression, the first one is a reactive depression which occurs as a result of a past loss (i.e. loss of body functions of strength). The second form is caused by the impending losses (i.e. loved ones, home, their own lives and all they have known).

If a patient has enough time and has been given some help in working through the previously described stages, he will reach the fifth stage, acceptance. He is usually tired and in most cases quite weak. Acceptance should not be mistaken for a happy stage. The stage of acceptance is almost void of feelings, as if the pain had gone and the struggle is over. When the dying patient has found some peace and acceptance, his circle of interest diminishes and he desires to be more alone.

Schneidman (1973) states that his observations did not lead to the same conclusions identical with those of Kubler-Ross. He sees people as going through the different emotions described by Ross but does not believe they are necessarily stages of the dying process, nor lived through in that order. Schneidman sees the only two definite stages as intrapsychic, preparing oneself for death, and interpersonal, preparing the loved ones to be survivors.

In <u>Coming to Terms With Death</u> Cutter (1976) sets out stages that deal with the options people face as they realize they are dying. The first stage which many people rush into is that of exhiliration of achieving a long-wished for desire. They rush into achieving this end no matter of consequences. The second stage is an emerging of a growing disillusionment, the desired goal was not all it was cracked up to be. The third stage is regretting the time, energy, money and whatever else was given up in order to indulge the first choice. At this stage, patients seem to find new wisdom that permits the patient and his survivors to incorporate into the dying process all those habits of prior life that provide meaning and satisfaction. These conclusions were drawn as he worked with patients.

The concept of stages in response to life-threatening illness are discussed by Guello, Cherico, and Shadick (1974). These researchers feel that patterns of responses appear to emerge through a series of successive stages. The first four stages correspond with Ross's stages, but they are entitled Stage 1 - Shock, Stage 2 - Anger, Stage 3 - Grief and Anticipatory grief, Stage 4 - Bargaining or "Promissory Note" Behavior. From this point on, the theories differ somewhat, with Stage 5 being the period of uncertainty. It is at this point in the illness a major intervention takes place, such as a specific treatment of surgery. The patient feels an uncertainty as to the outcome; will the disease be arrested or will the surgery be successful, or will these methods be unsuccessful. Patients experienced a heightened anxiety and uncertainty about the outcome.

7.

Stage 6 is renewal and rebuilding. This stage begins when the patient knows the outcome of the treatment and understands his limitations and can begin to again plan for his life, pick up some aspirations for living.

Integration of the experience is the final stage, where the patient integrates the serious illness into his life. It is a type of experience that alters one's sense of the past and present and one's approach to the future. These stages came through observation.

Still another set of stages are defined in terms of psychosocial care (Weisman, 1974). Stage one is the period from the onset of symptoms until the diagnosis is made. Few people are under medical observation when Stage one begins and may need encouragement to seek help. The psychosocial problems are related to delay, denial and postponement.

Stage 2 is the interval between diagnosis and the onset of terminal decline. During this stage the psychological problems are recognized by changes in the equilibrium of denial and acceptance. The major defense operations are those of mitigation and displacement.

Stage 3 starts when active treatment is found to have diminishing value. Therapeutic emphasis gradually shifts from cure to control, to symtomatic relief and nursing care. Patients are increasingly faced with the prospect of yielding personal control to someone else and of coming to terms with cessation. Stage 3 is sickness until death.

Lauren Trombley, a young psychiatrist, died some eight months after he discovered that he was suffering from leukemia. He wrote a self-study of his psychological journey to death during the last two months of his life. The following shows the stages he progressed

through and how he felt about his dying (Trombley, 1976).

The first reaction after being told he had leukemia was one of shock, then shifted into a deep and bitter disappointment that he had been cheated out of all hopes and aims that he had set for himself. He found that he had to take time off due to his illness, and he felt he was not performing in his work as well as he should, thus causing guilt. During this stage, he had pangs of remorse but did not feel frightened or angry at his situation nor did he have any feelings of denial.

At first, Dr. Trombley was kept busy setting his "affairs in order" and he felt this decreased his anxiety. There was an enormous mobilization of energy to get things accomplished. He and his wife took time to do many things together they felt enhanced their lives.

In dealing with other members of his family, his parents, and his children by a former marriage, he was open and honest. The children first reacted and he felt some of his colleagues may have experienced the same feelings of "If I get close to you, will I get the disease and die too?"

He stated,

At all times I make it clear that I in no way want to avoid open discussion of my illness. People wrongly assume that a sick person should be 'protected' from strong and particularly negative feelings. The truth is that there is probably no more crucial time in a person's life when he needs to know what is going on with those who are important to him (Trombley, 1976).

Dr. Trombley felt his illness made him much more aware and understanding of the feelings of all people he came in contact with, he was more sensitive to what was going on around him and he found himself hungering for every sensory experience that he could absorb. The world

seemed to offer more beauty and there was a heightened awareness of sight and sound. There seemed to be a culmination of learning experiences that helped him replace his feelings of despair and anger.

The Indignities of Dying

The majority of Americans today will die of chronic illness in a rather slow lingering fashion. Acute and unexpected death will continue to occur from heart attacks, accidents and violence. But for most of us, growing older and developing cancer, a failing heart, a failing blood circulatory system in the brain, will be our future (Krant, 1974 and Cutter, 1974).

A person with a fatal illness today finds himself in an uncomfortable position. There are few of the older, traditional supports such as religion, family ties and close communities to nourish him, therefore he has become dependent on professionals and institutions to minister to his needs. Successful as they are, the professionals seem more concerned with disease than with human meaning. There is a scarcity of attention paid to concepts such as finding help for the dying to find meaning, self-worth and dignity in their lives (Lerner, 1963).

As a population, Americans are less initiated into the intimacy of dying and death than ever before. The modern citizen has been so unprepared to think about death as a part of his life, that he feels helpless, lost and frequently over-dependent on the powerful professionals. He comes to his dying confused, angry, and in many ways, unprepared. He finds that his dying is not under his control but under the control of others (Becker, 1973).

Fearful as the confrontation with an abstract concept such as death may be for most people, the slow, lingering process of dying of a chronic illness is yet more distressing, for in the process of dying is the living loss of all those values that make life livable. Americans were brought up to cherish good health, success, cleanliness, independence, sexuality and good looks. There is little value seen in suffering (Krant, 1974 and Shneidman, 1976).

Dying is often feared as a possible time of physical distress. Reassurance is often sought on three aspects of dying - will it take a long time to die?; is it likely that there will be severe physical suffering?' will this be relieved? (Hinton, 1972 and Shepard, 1975).

In a study in which district nurses provided reports from a survey of seven thousand cancer patients over two-thirds had moderate to severe pain. In another report on the care of terminal care of cancer patients at home, relatives were asked if patients appeared to have enough sedation and relief from pain. It was reported that about onefifth of them had physical distress that was not relieved and almost another one-fifth had a lesser degree of comfort (Aitken, 1959).

The suffering that emerges in illness is not just physical pain but involves the loss of a good self-image and self-esteem. The dissolution of the body in chronic wasting disease is the dissolution of those things that make life worthy. Along with the dissolution of the body is also the fear of the loss of mental ability; will I be able to function as a human being, competent to make my own decision? With those losses or the fear of loss, the very meaning of life begins to fade, to be replaced by feelings of agony, anger, futility and hopelessness (Cutter, 1974).

The feeling of hopelessness was described by a patient who kept a diary for Robert Kavanaugh. The patient states:

As I declined physically, an aura of hopelessness descended around me, the most fearful atmosphere I ever faced. It was terrifying. The entire hospital smacks of hopelessness once the secret of your doom spreads down the corridors. I fear the whispering around me, the sadness etched on faces and the babying approach. You feel cut off. I watched them do it to the lady in the room with me and then to me (Kavanaugh, 1974, p. 56).

A highly cherished ideal is the sense of independence. A fatal illness brings about the gradual loss of independence, with an increasing need to be dependent on others, known and unknown. In a society that cherishes the notion of appearing independent, self-reliant and always able, the image of the loss of such characteristics as occurs in the slow process of dying is a crushing one (Lamerton, 1973 and Krant, 1974).

American culture has been described as the worship of the living, with so much emphasis on progress, strength and vitality. In such a society, dying can be a terribly lonely and desperate experience, as indeed it often is (Lifton-Olson, 1974).

"I don't want to become a burden to my family" are the words often spoken by the terminally ill. The interpretation is given that one has value only when able to do, doing for others and for self, and becomes a burden when they can no longer behave in this manner. People are frequently distressed at being considered a burden and will choose to go to a nursing home or hospital. In doing so they feel isolated and separated from their loved ones, along with a feeling of rejection (Lamerton, 1976 and Hinton, 1972).

One patient discusses these feelings:

I cannot adequately describe my growing horror of being rejected by anyone. I feel a need to be overly kind and agreeable, to put up with grief from anyone, always saying 'yes' when the answer is really 'no'. Any hint of rejection intensifies my fear of dying alone, abandoned, isolated and in terror (Kavanaugh, 1974, p. 57).

It is a common-place observation that as illness progresses and death approaches, friends and family do tend to recede. The patient's expectation of isolation becomes a reality and the loneliness of dying is reinforced by the absence of responding, communicating, living presences. Even if loving people do not physically abandon a loved dying one, there is frequently intense embarrassment as to what to say or how to talk with a person who has no future. The healthy, made uncomfortable by the presence of altered bodies, of weakened faces, of smells and sights of dying, often wish to be away and not reminded of the fraility of the human potential. In this way, loved people may die in a social and needed sense long before they are biologically ready for death (Sudnow, 1967; Kalish, 1966; and Shneidman, 1976).

In dying not only is muscular control lost but there may also be the loss of control of one's simple bodily functions such as seeing, feeling, hearing, and, perhaps even more important, urinating and defecating, eating and cleaning. The vision of oneself as a helpless thing lying in bed unable to wash, unable to eat by one's own strength, unable to void or eleminate in privacy, is deeply upsetting. One patient stated that dying arouses fears of indignity in a proud person, that were greater than she thought she could bear. The rare times she contemplated suicide were when her bodily functions got out of control as she lay in a puddle or mess too embarrassed to tell anyone. When they came near her to freshen her, she pretended to be asleep, often wishing it were forever (Krant, 1974 and Kavanaugh, 1974). Many of the illnesses command much medical attention. These illnesses are a threat to a person's narcissistic self-image. A person's concept of his self-worth is often invested in a particular part of the body, or a living style and the way a person sees and interprets a particular organ or body part plays enormously on his sense of integrity, self-worth and his perceived ability to be liked and loved. A fatal illness such as cancer frequently results in disfiguring surgical procedures such as bowel resection, with a subsequent colostomy altering the flow of fecal materials, or a breast amputation as well as limb amputations.

For the patient who is not cured but only temporarily benefitted, this surgical alteration can be the first of a series of assaults that increasingly threaten the sense of attraction, livingness, and worthiness. Drugs and deterioration of the body as the disease takes its toll add to this feeling of little self-worth. One patient felt every visitor became a peeping tom, looking at her failing hair, sinking face, peeling lips, bleary eyes and thinning, yet bloated, body. This can do much to destroy an individual's self-esteem (Shepard, 1975; Krant, 1974; and Kavanaugh, 1974).

A slow dying process puts more and more constraints upon daily options. The meaning and pleasure of food changes, the pleasures of deciding the where and when to go diminish, the ability to enjoy the outdoors decreases, the sensual pleasures of seeing and touching recede. Gradually, the patient is deprived of all they love of this earth, the people, all things, places, work, even the favorite garden spot and pet, as well as his own body. The patient is so unsure what death brings that it seems impossible to think of giving it all up. The

terminally ill often react with mourning and grief, and justly so, for who has more to lose than the person who is dying (Krant, 1974; Cutter, 1974; and Keleman, 1974)?

Suggestions for Working With the

Terminally Ill

No matter how one measures his worth, a dying human being deserves more than efficient care from strangers, more than machines and spectic hands, more than a mouth full of pills, arms full of tubes and a rump full of needles (Hinton, 1972).

His simple dignity as a man should merit more than furtive eyes, reluctant hugs, medical jargon and phoney promises for a tomorrow that will never come. Yet to most people, the problem of facing death with someone we love catches us utterly unprepared. In most cases, people have no idea how to treat the patient - whether or not to tell the truth about his condition (Kavanaugh, 1974 and Taves, 1974).

In the last two decades, professionals have been searching and trying to find some solutions to these problems and develop ways to help the terminally ill, although there still needs to be much more research done (Ross, 1975; Shneidman, 1976; and Krant, 1974).

There is still much debate over whether or not to tell the patient he has a terminal disease. In one study, 560 patients were asked whether they would wish to know of a fatal diagnosis. Eighty percent desired this information, twelve percent did not and the remaining eight percent were unresponsive. Another sampling came from a Minnesota survey of one hundred cancer patients and one hundred noncancer patients. Eighty-nine percent of the cancer patients wanted to be informed if they had inoperable malignancies and eighty-two percent of the non-cancer patients wished to know if they ever developed a fatal tumor (Shepard, 1975). The consensus of most of the available literature agrees that the majority of the people wish to hear the truth (Kubler-Ross, 1975, Kavanaugh, 1974; Caughill, 1976; Lamerton, 1976; Crane, 1975; and Shephard, 1975).

However, the manner in which this information is given is critical. When possible, it is best to prepare the patient gradually by letting the patient know that a serious diagnosis is a possibility and at the same time outlining proposed treatment in event their suspicions are verified. Patients need to know that their doctors will hold a balance between the need to investigate all aspects of the disease and yet not give false hope or pursue treatments that are useless (Kubler-Ross, 1975; Lamerton, 1976).

It is best to have conversations with the patient and his family at the same time. This gives all concerned the feeling that everything has to be said is being said and that nothing remains for "back room" conversation. The first interview is not always the best one for full details to be given. During the first interview the patient and his family are expectant and tense. The patient should be told that he will probably have more questions to ask at the second visit and that the doctor will be available for further discussion at that time (Trombly, 1976). This should encourage open communication between the doctor, the family and the patient. It is helpful for a patient to be able to discuss his views, how he feels about dying, his concerns for his family. This potential for intimacy ought not to be denied those who are leaving life (Hinton, 1967 and Krant, 1974).

The patient who is approaching death wants the opportunity to talk about some daily things because they are the only realities they have (Cronk, 1972; Taves, 1974; Troup and Green, 1974).

One of the most important phases of communication is developing a listening ear - just listening or even holding a hand silently late at night may be the most important communication that can be given; along with letting the patient know that professionals care and families saying "I love you" (Lamerton, 1976 and Taves, 1974). It would be helpful for the doctor, when indicated, to discuss the patient's situation with the patient's clergyman, then the minister can give combined help to the patient and his family as long as it is needed (Dennison, 1972).

The proper administration of pain medication is a major factor in aiding the patient, along with good nursing care. The patient should be surrounded by pleasant, caring people and he should not have to worry if he will have adequate care now nor as he grows weaker. Affection and trust should develop between the dying person and the people who look after him. It is inconceivable that the relationship between the patient and the doctor remain impersonal (Shephard, 1975; Kubler-Ross, 1975; Hinton, 1972; Lamerton, 1976; and McCoy, 1974).

The chronically ill patients have too much time to think and they should be encouraged to do things to help them keep their self respect and feel useful. It is recommended that the patient be put under the supervision of the occupational therapist, who will aid him in finding and accomplishing in jobs which will fit their situation as long as possible. Later, the therapists may make systematic use of games of all kinds (Lamerton, 1976 and Weisman, 1974).

Let the dying patient live - while he lives as normally as he possibly can. Try to maintain an emotional and social environment consistent with the patient's past life style when circumstances permit. This, along with being allowed and required to make decisions for his own life as well as decisions in the life of those he loves, will help him preserve his self-esteem and self-recognition (Taves, 1974; Kubler-Ross, 1975).

It is important to maintain some type of social life to the end. Even though his working life and consequent status among his fellows have come to an end, he wants to know his personal ties remain. He also wants to know what is happening in the life of his family and be included as a part of it (Hinton, 1972; Kubler-Ross, 1975; and Lamerton, 1976). Some ways that family members and others interested in the patient may help fears of isolation and the loneliness is to maintain frequent visits; even in the state of a coma it has been established that the hearing is the last sense to leave and even if the patient may not respond he may still hear and gain from the presence of a loved one (Hunt, 1971; Lamerton, 1976; and Troup and Green, 1974).

In dealing with visits, if the patient expects you at a specific time, make it a point to be on time. There is nothing more difficult for someone who is confined in a hospital bed than to wait for someone who isn't (Taves, 1974).

Emotional support is of vital importance at all times. All fears and needs are exaggerated during the last days as the transfer from home to the hospital occurs. What is needed more than anything is comfort, compassion and reassurance. This can be provided only by another human being, no drug can act as a substitute (Gubrium, 1975;

Krant, 1974; Kubler-Ross, 1975; Hinton, 1967; and Lamerton, 1973).

Even with various medical professions working to develop staff skills for administering to the terminally ill, there has been very little empirical research conducted. The few reports of psychotherapy with dying patients have been basically ancedotal such as the work of Kubler-Ross (1969). However, Zuehlke and Watkins (1975) conducted a study to investigate the effectiveness of a psychotherapeutic technique, logotherapy, with the terminally ill patients. The basic hypothsis was that such patients could be helped to cope with emotional stress created by their poor prognosis and to establish new perspectives on the message and purpose in their lives.

The subjects were twelve male volunteers, patients hospitalized in a Veterans Administration hospital in South Dakota. Patients were assigned alternately to a treatment or to a no-treatment control group. The instruments were two dependent measures to allow the patients to report their perceived death-related anxiety and the sense of purpose and meaning to their lives. The Death Anxiety Scale is a 15 item, truefalse questionnaire designed to measure the degree to which a person reports anxiety feelings related to fears of death. The Purpose of Life Test is a 20-item, 7-point Linkert-type attitude scale designed to measure the degree to which a person reports a sense of meaning and purpose in his life. This test is based on concepts derived from Frankl's logotherapy.

All the subjects were given the tests and then those in the treatment group received six, forty-five minute sessions of logotherapy over a two-week interval. At the conclusion of therapy, each patient again filled out the dependent measures.

Changes between the treatment group and no-treatment, control group were analyzed by a multivariate analysis of covariance. The past treatment scores demonstrated an overall significant difference (P < .01) between the treatment and control groups.

The researchers felt that the central hypothesis was supported and the study showed the treatment groups were better able to get in touch with their fear anxieties towards death. The multivariate finding further suggested that the reported sense of worthiness, meaningfulness, and purposefulness in the lives of such patients can be improved by psychotherapy (Zuehlke and Watkins, 1975).

Whitman and Lukes set up a program and developed guidelines for using behavior modification for the terminally ill. This study is made up of the guidelines used for the treatment groups and a summary of the outcomes, using again the ancedotal approach rather than empirical research.

The guidelines are:

- 1. The major behavior problem must be defined.
- The patient must have honest, complete, accurate information about diagnosis, prognosis and estimated life span and have the program explained.
- The patient's family must be informed of the patient's health status and become involved in planning for his care and treatment.
- 4. The establishment of a base line is essential, the staff must identify their own positions regarding the patient's behavior and explain that they expect the patient to cooperate.

5. Do not waiver in the approach.

6. Expect behavior to get worse before it gets better.

7. Praise all positive behavior and accomplishments immediately.

The authors found the patients generally feel a sense of relief when their maladaptive behavior is altered.

The patient is ultimately helped to deal more realistically with his disease, communicate more effectively with his family and improve the quality of his remaining days (Whitman and Lukes, 1974).

At the Lutheran General Hospital in Park Ridge, Illinois, every patient receives a visit from a chaplain. Due to this program, a research project was set up. In this project, a terminally ill person was defined as one whose illness is such that: (1) death is probably within a year, if the condition persists, and (2) there is no known cure for the patient's condition.

The offer of counseling was made by the chaplains to eighty-four candidates and seventy-four patients, eighty-eight percent accepted the offer.

The major dependent variable in this study was the Emotional Adjustment Scale. The Scale was designed to measure the extent to which a terminal patient was able to cope interiorly and exteriorly with his limited life expectancy. The E A Scale consisted of six questions which the chaplain rated on the basis of the patient's words and behavior as well as on information obtained from the staff and the patient's family. The questions measured the presence or absence of anger, guilt, anxiety, depression, and also the ability of the patient to verbalize his feelings with his family and friends.

The discomfort scale was formed from five items. The chaplain

evaluated the patient's amount of pain, disfigurement, dependence on others, difficulty in eating, and difficulty in sleeping. The relationship between religion and emotional adjustment was examined from the aspect of religious affiliation, religious beliefs and the quality of religious orientation. Four categories of religious orientation were considered: intrinsic, extrinsic, indiscriminately pro-religious, and indiscriminately non-religious.

Previous experience with the dying persons was analyzed from the standpoints: (1) Whether or not the patient had ever talked frankly and openly about death with someone who was dying, (2) Whether or not someone he was close to accepted death with an inner peace, (3) Whether or not he had been close to someone who was angry or upset to the end of his life.

The most important factors in predicting emotional adjustment were the level of discomfort, previous close contact with a person who was dying. As expected, a strong negative relationship was found between the level of discomfort and emotional adjustment, sixty-six percent scored high on the Emotional Adjustment Scale as compared to thirty-six percent of patients with high discomfort.

The previous experience with dying persons had a noticeable effect on the level of emotional adjustment. Of the patients who talked openly and frankly with a person whom he knew was dying, seventyseven percent had higher adjustment as compared to forty-eight percent who never had this experience. Sixty-six percent had higher adjustment if the relationship with the dying person was at peace, compared to forty-four percent had higher adjustment if the dying person was angry.

The study found concerning religious beliefs, fifty-six percent

who believed in God had higher emotional adjustment than the twentynine percent of non-believers. Those patients who showed a great concern for family, friends, physician, and the local clergyman also had a higher emotional adjustment.

In relation to sex, forty-four percent of the males had high adjustment as compared to fifty-five percent of the females. Age was a variable as those subjects under forty had only twenty percent high adjustment compared to fifty percent over forty. The type of disease had no effect at all on adjustment. This study has shown how various types of situations can affect emotional adjustment and suggests more people working with the terminally ill need to set up research and share their findings (Carey, 1974).

Families of the Dying Patient

The consistently casual treatment of family members in almost all hospitals demonstrates that medicine does not yet consider the family an important factor in patient care. Families and friends of dying patients can become as bewildered and neglected as the patients themselves (Kavanaugh, 1974).

The dynamics of the families' responses are complex and there is limited consensus on work done in research (Edits, Schoenberg, Goldsberg, Carr, Peretz, Kutscher, 1972). Kubler-Ross (1969) states that we cannot help the terminally ill patient in a really meaningful way if we do not include the family.

There has been some work done that identifies some of the anxieties and needs of the family. These are:

- The family has a great deal of anxiety over the suffering and disability the ill may experience (Hinton, 1972; Krant, 1974; and Cutter, 1974).
- They have a sense of hopelessness and loss. The grief process begins at the knowledge of the disease (Hinton, 1972; Lamerton, 1976; and Schoenberg, et al., 1972).
- The families need to support each other rather than blaming themselves or other family members for the cause of illness or the state of affairs (Krant, 1974 and Hinton, 1972).
- Many times the spouse or close family members need some extra attention rather than always "showering" the attention on the patient (Hinton, 1972).
- Families often feel ashamed of their emotions and are not encouraged to show them (Taves, 1974 and Shephard, 1975).
- Families often fail to realize the need for help and do not seek aid (Hinton, 1972).
- Families assume too much of the responsibility, taking over, protecting the patient and always masking their own tiredness and exasperation.
- 8. Not understanding that they need to look out for themselves too, the family needs to know it is all right to laugh, cry and go out. The patient who is dying is a human being and it takes away his integrity to give himself and his responsibility for his life up entirely to someone else because he is dying (Taves, 1974 and Shepard, 1975).
- The family has a strong need to communicate with the doctor openly. No doctor is God. Families have a right to ask the

doctor questions and to get answers. If he is too busy, the family has a right to find someone who isn't. Sometimes a doctor will seem to be avoiding the family to avoid giving unpleasant answers. Family members should be frank with him and expect frankness in return (Taves, 1974; Hinton, 1972; Troup and Greene, 1974; and Shepard, 1975).

A cancer care center that services a fifty-mile radius in New York City has developed the following guidelines for families facing cata-

strophic illness:

- Do not attempt to go it alone. Seek some kind of outside professional advice.
- 2. Find out exactly what your resources are. Often there is insurance for helping with expenses.
- 3. Write down a list of the real issues involved. It does no good to become paralyzed. Costs, care of children, aims and goals that need to be met.
- 4. Do not deny the problem. Faced early enough, mutual decisions made by everyone not only prepare for the ultimate death and loss of family member, but seeing that those who remain are not left with intolerable burdens (Taves, 1974, p. 98-99).

In the book, <u>Someone You Love Is Dying</u>, Dr. Shepard has recorded interviews with terminal patients. One of these patients, a young woman named Karen, focuses an interview on the problem of dying from the prospective of the family. She states:

I think it is harder for the family to adjust to a death than for the individual who is dying. If I could write a book to help families cope, I would tell them, 'To think of themselves, not just the individual involved, because many of them have their own feelings. There is nothing wrong with crying. You want someone to laugh and cry with you, not just laugh. To know someone cares about you means they have to cry sometimes and not just be around in the good times. You do not stop caring for the other person just because you are sick, so they ought not to spare you their own bad news.

'I would ask the doctors to spend more time with the families. Of necessity, their main concern is the patient, but they would help the patient in the long run if they would spend more time with the families' (Shepard, 1975, p. 102-103).

Summary

Facing one's death, or the death of a loved one may well be the most serious emotional adjustment one will face in their lifetime. Even though it is evident that in the last ten years, significant gains have been made in determining emotional needs and the professionals that help with the terminally ill have been striving to find some workable solutions.

While much has been written on death and dying, little research exists in the success of various methods to aid the terminally ill adjust, nor have specific methods been developed. There are few guidelines for ministers, counselors, or family members in working with chronically ill patients.

Although there has been much literature written about the grief process after death, little can be found for helping the family members cope with their own emotional stress on the day-to-day basis as they watch their loved one dying. It is, therefore, the purpose of this study to determine some methods which would be useful to a counselor in aiding the patient, as well as the patient's family, in their time of adjustment to illness and death.

CHAPTER III

METHODOLOGY

Introduction

The purpose of this research was to determine methods that are most helpful to terminally ill patients as well as their families, to better accept, cope and adjust emotionally to this crisis, by assessing the perceptions of: doctors, ministers, psychologists and psychiatrists, and survivors of patients that died from a chronic disease. The study made use of modified Delphi Technique to determine these methods. The investigator proposed to find a rank order of the methods according to the priority established from the way the participants rated the importance of the generated statements. Another aspect investigated was whether or not there was any difference in the ratings given to the statements by the various groups.

The purpose of this chapter was to describe the Delphi Technique, the method by which the sample was selected, the design of the instrument, and the procedure of data collection and analysis.

The Delphi Method

The researcher chose to use the Delphi method as it attempts to take individual opinions and compile a meaningful response and to get an expert opinion without bringing the experts face to face. It is an

orderly, planned program of sequential individual interrogations. The method was developed by the Rand Corporation some twenty years ago in their "think tank" in Santa Monica, California. Although this technique was developed mainly as a forecasting model, many today see the technique as a way to encourage consensus or a convergence of opinion (Weaver, 1971).

Some recent experiments that have been performed by Rand Corporation indicated that when opinions are involved, face-to-face discussion may result in a group opinion that is less accurate than simply the average of the individual opinions without discussion (Dalkey, 1968).

Weaver (1972, p. 47) reports in his critique of the Delphi methods that, "although Delphi was intended as a tool for scientific and technological forecasting it . . . may aid in probing priorities" Scanell (1972, p. 11) in his study concluded, "the Delphi technique provides a mechanism for allowing individuals to express opinions and to modify them on the basis of the collective judgement of a group of people in gaining a consensus of opinions."

Berty (1972, p. 12) indicated that Delphi is "A professionally sound approach devised to provide useful information not only to educate decision-makers but also facilitates a consensus being reached." The groups concept was very aptly explained by Dalkey (1972, p. 15) with the statement:

There is a kind of technology for dealing with opinion that has been applied throughout historical times and probably in more ancient times as well. The technology is based on the adage 'Two heads are better than one' or more generally 'no heads are better than one.'

On the other hand criticism has been directed at the use of the Delphi technique. Weaver (1972) in his critical review of the Delphi

technique indicates problems which could limit the use of results obtained through these studies. He states:

The education Delphi's are in no way startling or sensational. That is obvious to the casual observer. There is a serious sterility in the process of summarizing mass information into narrowly terse statements. There is a serious absence of any effort to probe beneath the surface for explanation (p. 25).

However, it has been indicated that general interest in the Delphi technique increased significantly, brought about by the industrial studies of forecasting technological events and resulted in large increases in application by educational organizations (Dalkey, 1968). The procedure as Pfeiffer (1968) explains it, generally succeeds in its objective of encouraging convergence of opinions. In an attempt to identify changes in American education, the Institute of Government and Public Affairs at the University of California in Los Angeles used the Delphi technique. After the study was completed, Pfeiffer (1966), reports that the results were very instructive, whatever their validity and that the procedures were looked upon by almost all of their participants as potentially very useful in educational planning at all levels.

Several variations of the Delphi technique have been used but the most common procedure is as follows: First a questionnaire or other instrument regarding primary issues of concern is developed. This instrument is usually developed by a panel of experts or through nonstructured data collection methods such as open-ended questions. This instrument is then distributed to a group of respondents selected for data collection. Statements from the first round results are provided to the respondents and they are to rank the statements. Feedback is usually in the form of means or medians on each of the items.

The Delphi procedure in this study was carried only through two

29

V

rounds because it was not the intent of this study to reach a group consensus. Instead it was the propose to determine by an unstructured and unbiased external method a true expression of the participants' perception of methods most useful in aiding the terminally ill patient and their families. This was a method of letting the people interact with each other without exerting any initial influence on one another's opinions; also, this approach tended to eliminate investigator's biases.

The basic characteristics of the Delphi procedure are: (1) anonymity (2) interaction with controlled feedback and (3) statistical group response (Weaver, 1972).

Selection of the Sample

The population used in this study was a randomly selected stratified sample. The investigator used the six congressional voting district divisions to divide the state, as they are already divided so that there is an equal representation of the rural and metropolitan population of the state of Oklahoma (see Appendix A). According to the physical size of each district, county seats were randomly chosen from which participants were then randomly selected (see Appendix B for list).

Of the 240 participants, there were 60 in each of the following four groups. (1) ministers, (2) medical doctors, (3) psychologists and psychiatrists, (4) survivors of terminal patients.

The names of the participants were chosen randomly from the telephone director in each of the cities that had been randomly selected in each of the sixth districts. - Here

Names of the survivors were chosen from a list compiled from newspapers in each of these same areas. Newspapers used in the selection were printed between January 1 to December 31, 1976, and gave death announcements as well as the cause of death and the names and address of the next-of-kin.

Due to the specialization of the psychologists and psychiatrists, and the fact that their practices were located in the heavier populated areas, the names were randomly selected from the telephone directory throughout the sixth districts whenever possible, with the remainder of the names being chosen from directories in the more metropolitan areas. This was done in order to maintain an equal number of participants (see Appendix C for list of areas used).

The study initially involved 240 persons selected at random; of these 140 actually participated in the Delphi study. In order to increase the return rate, a follow-up letter was mailed two weeks after the original mailing (see Appendix F). At the end of another week the return rate was increased by 20%. Table I shows the number and percentage of the returns for all of the groups participating in the study.

The results showed the only group which did not have a return rate of over 50% was that of medical doctors. The minister population had the highest return rate of the groups polled.

The data received was from a cross section of the state, being almost equally divided, urban and rural.

	Number	Re	Returns	
Groups	Sent	N	%	
Ministers	60	42	70	
Survivors	60	34	57	
Psychologists & Psychiatrists	60	. 39	65	
Doctors	60	25	42	
Overall	240	140	59	

NUMBER AND PERCENTAGES OF PARTICIPANT RETURNS

Research Questions

The information to be obtained through the opinions and the perceptions of the four groups who are involved in working with the terminally ill may indicate that some changes are needed, certain groups may need to become more active, different priorities may need to be considered, all four groups may agree that a certain group of methods is the most useful or there may be opposing views among the groups.

To gather the necessary information, the following questions were proposed:

Research Question Number One: What are the statements of the perceived methods to best help the terminally ill patient and their families generated by experts in the four groups?

Research Question Number Two: What are the rankings of the statements generated?

Research Question Number Three: Do the rankings of the statements generated vary within the individual groups?

Research Question Number Four: Is there a difference between the group's responses?

The Opinionnaire

In order to answer these questions the investigator developed a questionnaire using the Delphi technique of interviewing experts in the randomly selected population and then sending the questionnaire out to the total population for ranking.

Traditionally the "Delphi Technique" has been used for forecasting by a panel of experts (Dayton, 1970). It is beginning to be used more and more for the purpose of collecting opinions as it was used in this study. The procedure used to generate the opinionnaire via the Delphi technique is outlined in the following paragraphs.

After the populations had been selected the investigator interviewed three experts from each of the four populations, ministers, medical doctors, psychologists and psychiatrists, and survivors of patients of a terminal disease. They were ask to generate five statements containing methods which they felt would be most helpful to the terminal patients and five statements which would consist of methods that would be most helpful in aid to the family of the terminal patient.

In the next step, the investigator reworded and combined all similar responses to eliminate redundancy and ambiguity to produce the opinionnaire. This list of statements with a letter was mailed out to the randomly selected participants for their ratings as to how they perceived the importance of the statements as to the role they would play in aiding the terminal patients and their families (Appendix D and E). A seven-point rating scale was provided for the responses to each item; one being the most important. The statements were returned by mail. In order to keep the opinionnaire anonymous, and yet let the investigator know from which group the response was returned, it was color coded. Bright pink for psychologists and psychiatrists, pink for medical doctors, gold for survivors and light blue for ministers.

Treatment of the Data

In order to answer research question, two of which dealt with the individual group's rankings, the investigator used frequency and percentage tables for each of the statements, for both parts of the questionnaire. Part A being the methods to aid the terminal patient, Part B, being the methods to aid the family.

To answer research question three, which dealt with the rankings of the individual groups, on each statement to determine which groups varied most in their rankings, the investigator calculated the variance of the responses to each statement in Part A and Part B, and then computed a mean variance for each population for both Part A and Part B.

To deal with research question four, which asks if there are differences in the various groups rankings, the investigator utilized a Chi Square test on each individual statement to determine if there were significant differences in the way the groups responded.

Assumptions

The basic assumption of this study is that the people who work and

have had experiences with the medical, psychological, spiritual and personal needs of the terminally ill and their families should be the best qualified people to use for the research. They should make suggestions for methods to help aid in adjustment and acceptance of this situation.

For the purpose of the study, the additional following assumptions will be accepted by the investigator:

- The responses will serve as predictors of the surveyed groups' perceptions of ways to help the terminally ill and the family.
- The respondents are capable and will reply in a way that would reflect their honest expressions.
- The non-respondent's responses would not have been significantly different from the respondent.

Limitations

- The sample was limited to medical doctors, ministers, psychologists and psychiatrists, and survivors of chronically ill patients. This study was not to be representative of the entire population of Oklahoma.
- The psychologists and psychiatrists were not distributed throughout the entire state of Oklahoma.

Definitions

<u>Doctor</u> - The word doctor as used in this study is in reference to those individuals who are qualified to practice medicine.

<u>Terminal Patient</u> - The terminal patient is an individual who is aware that he has a fatal disease which allows the individual and his family a chance to reflect upon the eventual death.

CHAPTER IV

PRESENTATION AND ANALYSIS OF DATA

Introduction

The purpose of this study was to determine counseling methods that were most helpful to the terminally ill patients and their families, by assessing the perceptions of doctors, ministers, psychologists and psychiatrists, and survivors of patients who died from a chronic disease. This was accomplished by using the Delphi Technique and asking three experts in each of the four groups mentioned above to generate statements. A sample from each of the four groups were asked to rate the importance of the generated statements.

The data relating to the research questions will be presented in this chapter.

Results of the Data Pertaining to Research

Research Question Number One

What are the statements of the perceived methods to best help the terminally ill patient and their families generated by experts in the four groups?

In order to answer this question, the investigator interviewed three experts from each of the four populations. The experts were ask to generate five statements containing methods they felt were most

useful to the terminally ill patient, and five methods most useful to the family of the terminally ill. These statements were reworded and combined to eliminate redundancy and ambiguity. The statements are presented in Table II and Table III. The experts generated 25 individual methods for the terminally ill patient and 29 methods to aid the families. The investigator found that from the 25 statements generated for the terminal patient, 6 statements (numbers 2, 7, 15, 16, 20 and 24) and from the 29 statements for the family 5 statements (numbers 3, 6, 8, 12 and 17) were almost identical to suggestions found in the review of literature. Thus the experts generated 43 statements that are not the same basic or concrete statements that the review of literature shows are now being suggested.

Research Question Number Two

What are the rankings of the statements generated?

To arrive at an answer for this question, a frequency and percentage distribution was calculated for each individual statement. This data may be found in Appendix G. The results showed the top ten ranked statements for the terminal patient found in Table IV. The top ten ranked statements for the family are presented in Table V.

In dealing with the statements which had the highest percentage and frequencies for the terminally ill patient, the data shows that the top five statements all had at least one of the populations 100% in agreement that this was the most important statement. Each population had ranked a different statement, with the doctors being 100% in agreement on two statements of the top five. The last five of the top ten statements were ranked high in most important, but also showed rankings

TABLE II

STATEMENTS OF THE PERCEIVED METHODS FOR HELPING THE TERMINALLY ILL

- 1. Provide support during this time, as this is the greatest loss a person suffers, it cannot be modified and must be accepted.
- Feelings of anger and hate are often expressed in dying and counseling techniques would not alter this but accept it and help the patient vent these feelings.
- 3. Help the person articulate about what they feel will happen to the family and to themselves after they die.
- 4. Communicate through action and non-verbal behavior that the patient is not being abandoned at this moment in his life.
- 5. Help the patient talk out his situation, being authentic and real enough to accept and handle whatever the patient wants.
- 6. People should not put arbitrary crap on how the patient should behave; you don't have to act special to suit me.
- 7. Patients have a need for a high degree of emotional interaction from others; encourage friends and family to continue to come.
- 8. Develop an inner listening ear, to hear the patient's real needs and do not push your beliefs on them.
- 9. Let the patient and family know the church family is there, for strength or aid at any time.
- 10. Try to talk to the patient and family together, so patient will feel there is total honesty.
- 11. Help the patient deal with any guilt he may have about causing his condition (i.e., smoking, physical activity).
- 12. The patient has the right to be aware of the side effects that some medical treatments may cause, and should have the option to say no to these treatments and be allowed to die as natural as possible.
- 13. People should not be overly nice or pamper a patient because they are dying, causing them to feel less than human.
- 14. People working with terminally ill need to express some feeling or mood of security.

TABLE II (Continued)

- 15. Help patients find some hope, short term goals, give them a sense of purpose, a reason to continue to function.
- 16. Patients should have a choice in the options for them, they should be allowed to make these decisions, as it is their life.
- 17. Patients should not just be kept alive under artificial methods but be left the dignity of a human being.
- 18. Let the patient know you love him, God loves him, and God made him an individual with the strength to face the situation.
- 19. Don't approach the terminally ill with a miracle attitude, but pray that God's love will flow through us.
- 20. There is a need for good advice about places for good medical care.
- Young terminally ill patients and their families often need information about financial aid, as insurance won't cover the cost as medicare does for the elderly.
- 22. Hospitals should offer in their services a qualified counselor that the patient or the family might use if they so desired.
- 23. Professions working with the patients should have knowledge of their background to stimulate their memory of by gone happier days to console the ill.
- 24. Proper pain and nervous medication should be given to relieve anxiety and extreme stress conditions.
- 25. Make sure the clergy and church professionals make religion and death acceptable.

TABLE III

STATEMENTS OF THE PERCEIVED METHODS FOR HELPING THE FAMILY OF THE TERMINALLY ILL

- 1. Give the family some reading therapy, suggestions Ross's <u>On Death</u> and Dying, Moody's <u>Life After Life</u>.
- Be an empathic listener, respecting the existing crisis of the persons involved.
- 3. Help family work out how they should relate to the patient, offering a continuity of relationships.
- 4. Help the family through counseling session to articulate their feelings and help them develop as supportive a relationship with the patient as possible to facilitate his needs.
- 5. Aid the family so they will avoid putting their own emotional problems on the patient.
- 6. Help the family accept the finality of death and provide grief counseling before and after death.
- 7. Families need to remember and understand the patients are exposed to many strangers, on whom they must rely for their needs and many unfamiliar medical practices.
- 8. Remember the patient's family are under stress and should be allowed to ask questions about expectations for the future.
- 9. Help the family deal with guilt they might experience, (i.e., if we'd have just brought him to the doctor early, etc.).
- Discourage family from trying expensive unproven or quack medical cures.
- 11. Check to see if there is any unfinished business to deal with that professionals can help with (i.e., wills, financial issues).
- 12. Discuss with the family the level of awareness they have of the disease and what perception the family members have about what is going on. Encourage the family to talk to the doctor and get the facts.
- 13. Encourage the family to understand that just being there is important to the needs of both the patient and to the family.
- 14. Patients should not just be kept alive under artificial methods but be left the dignity of human being.

TABLE III (Continued)

- 15. Assure the family that God doesn't make any one suffer for their sins or the sins of others.
- 16. Assure the family God gives the ability to handle this situation.
- 17. Remind the family that they must face responsibility for the rest of their lives, so they must take care of themselves also.
- 18. Much support and help can come from friends who will sit with the patient, giving the family some free time.
- 19. Young parents who are caring for small children when they are in the hospital can't afford to hire outside assistance, need some type of service or aid.
- 20. Young terminally ill patients and their families often need information about financial aid, as insurance won't always cover the cost.
- Families need to be prepared for the disfigurement that may occur to their loved one.
- 22. In large hospitals where surgeons and specialists are busy and impersonal, patients and families need a service that will give support and explain procedures.
- 23. When rural patients and families must go to larger hospitals out of their community, a service is needed that will enable them to feel they can leave the patient for a short time and also receive information about the city concerning lodging and eating establishments.
- 24. Hospitals should offer in their services a qualified counselor that the patient or the family might use if they so desire.
- 25. Make sure the clery and church professionals make religion and death acceptable.
- 26. Keep family informed of diagnosis and progress.
- 27. Insist on family being present and do not make them feel they are superfluous baggage.
- 28. Insist that the family keep terminal patients from feeling they are creating financial problems.
- 29. Insist on family participation in helpful chores around the sick room.

TABLE IV

OVERALL GROUPS' RANKING OF TOP TEN STATEMENTS (PART A) METHODS FOR TERMINALLY ILL PATIENTS

Statement No.	Rank	Statement of Methods
1	lst	Provide support during this time, as this is the greatest loss a person suffers, it cannot be modi- fied and must be accepted.
12	2nd	The patient has the right to be aware of the side effects that some medical treatments may cause, and should have the option to say no to these treatments and be allowed to die as natural as possible.
4	3rd	Communicate through action and non-verbal behavior that the patient is not being abandoned at this moment in his life.
16	4th	Patients should have a choice in the options for them, they should be allowed to make these decisions, as it is their life.
5	5th	Help the patients talk out their situation, being authentic and real enough to accept and handle whatever the patient wants.
3	6th	Help the person articulate about what they feel will happen to the family and to themselves after they die.
15	7th	Help patient find some hope, short term goals, give them a sense of purpose, a reason to continue to function.
8	8th	Develop an inner listening ear, to hear the patient's real needs and not push your beliefs on them.
18	9th	Let the patients know you love them, God loves them, and God made them an individual with the strength to face the situation.
7	10th	Patients have a need for a high degree of emotional interaction from others; encourage friends and family to continue to come.

TABLE V

OVERALL GROUPS' RANKING OF TOP TEN STATEMENTS (PART B) METHODS FOR FAMILIES

Statement No.	Rank	Statement of Methods
20	lst	Young terminally ill patients and their families often need information about financial aid, as insurance won't cover the cost.
26	2nd	Keep family informed of diagnosis and progress.
13	3rd	Encourage the family that just being there is as important to the needs of both the patient and to the family.
2	4th	Be an empathic listener, respecting the existing crisis of the persons involved.
4	5th	Help the family through counseling session to articulate their feelings and help them develop as supportive a relationship with the patient as possible for facilitate his needs.
12	6th	Discuss with the family the level of awareness they have of the disease and what perception the family members have about what is going on. Encourage the family to talk to the doctor and get the facts.
27	7th	Insist on family being present and do not make them feel they are superfluous baggage.
9	8th	Help the family deal with guilt they might exper- ience, (i.e., if we'd have just brought him to the doctor early, etc.).
19	9th	Young parents who are caring for small children when they must be at the hospital and can't afford to hire outside assistance, need some type of service or aid.
5	10th	Aid the family so they will avoid putting their own emotional problems on the patient.

in both the neutral and least important positions.

The statements chosen for the ten most important methods touch upon several areas, dealing with many aspects of treatment; medical care, individual dignity, goals, meeting emotional needs and religious views.

Table V contains the rankings of the ten top statements for methods for the family. The results indicate that the top eight statements have at least one population in 100% agreement on the most important method. The statement chosen for the number one in importance had three populations in agreement; (1) ministers, (2) psychologistspsychiatrists, and (3) survivors.

The survivors were in agreement 100% on six of the eight top statements, while psychologists and psychiatrists were 100% in agreement on three of the top eight. Doctors were in agreement 100% on two statements and ministers were 100% in agreement on one statement. Thus it is obvious that the survivors rankings did influence the choices made in this portion of the study.

The ninth-ranked statement was again ranked high in the most important, but also had rankings in the neutral and least important positions. On the tenth choice the data reveals that the doctors were 100% in agreement.

The top ten-ranked statements were diversified but not as diversified as statements for patients. They dealt with financial aid, emotional needs of both the patient and the family, and keeping accurate information before the family.

Research Question Number Three

Do the rankings of the statements generated vary by the individual group?

To satisfacotrily answer this question, the variance was calculated for the individual statements. The results are presented in Table VI. A mean-item variance was also computed for each population and this information is presented in Table VII. The mean with the highest value identifies the population with the most variance in responses.

The data in Table VIII demonstrates that of all the populations used in the study, the doctors varied the most in their rankings of methods to help the terminally ill patients, while survivors varied the most in the rankings of methods to aid the family. The ministers were the most consistent in their rankings on both parts of the opinionnaire, and psychologists and psychiatrists were next.

The variance among the doctors in ranking seemed to be over many different statements, however the highest variance occurs in the following statements:

- Patients should have a choice in the options for them, they should be allowed to make these decisions, as it is their life. (5.44)
- Patients should not just be kept alive under artificial methods but be left the dignity of a human being. (5.04)
- The patient has the right to be aware of the side effects that some medical treatments may cause, and should have the option to say no to these treatments and be allowed to die as natural as possible. (4.96)
- People should not put arbitrary crap on how the patient should behave; you don't have to act special to suit me. (4.64)
- Let the patient and family know the church family is there for strength or aid at any time. (3.76)

TABLE VI

Psychologists						
Statement	Ministers N=42	Psychiatrists N=39	Doctors N=25	Survivors N=34	χ ² Values .	
1	2.34	2.06	2.07	0.47	8.02*	
2	1.80	2.70	1.76	1.68	10.35	
3	0.82	0.99	2.48	3.43	23.67***	
.4	.01	2.38	0.56	3.43	15.42*	
5	1.18	0.53	2.56	6.67	43.04****	
6	2.43	2.07	4.64	3.76	29.79****	
7	2.53	1.82	1.84	0.47	42.01****	
8	0.68	1.56	2.80	0.10	21.40****	
9	0.68	4.36	3.76	0.94	23.87***	
10	2.54	2.59	2.64	1.60	14.59*	
11	2.53	1.62	2.00	1.87	18.98**	
12	1.67	0.56	4.96	1.60	15.46*	
13	2.15	1.76	1.60	1.01	40.88****	
14	1.48	2.18	3.04	0.54	49.29****	
15	0.78	1.76	0.64	2.72	15.12*	
16	.04	0.85	5.44	1.66	43.25****	
17	1.73	2.31	5.44	6.32	16.68**	
18	0.85	1.71	5.44	0.00	29.30****	
19	0.38	1.58	2.00	6.54	64.49****	
20	2.78	1.48	1.84	3.11	55.20****	
21	0.93	5.05	1.20	3.51	27.28****	
22	2.14	2.86	2.24	4.09	17.37**	
23	1.30	4.18	1.84	3.60	58.15****	
24	3.24	2.95	2.64	2.21	35.76****	
25	3.12	3.38	2.24	6.67	14.69*	

VARIANCES AND CHI SQUARE VALUES FOR PART A

* = <u>P</u> < .05

** = <u>P</u> < .01

*** = <u>P</u> < .001

**** = <u>P</u> < .0001

TABLE VII

Family Variance Psychologists					
Statement	Ministers N=42	Psychiatrists N=39	Doctors N=25	Survivors N=34	χ ² Values
1	0.59	1.78	1.36	4.10	27.92****
2	0.37	0.00	1.36	4.03	28.19****
3	1.38	0.71	1.59	2.83	17.83***
4	9.77	0.40	1.02	4.35	26.75***
5	0.58	1.17	0.56	4.12	28.60****
6	0.36	0.18	1.42	4.07	75.90****
7	1.09	2.86	0.24	3.83	22.70***
8	0.92	0.99	2.06	1.15	25.54***
9	0.87	0.39	0.04	2.10	34.55****
10	1.12	0.75	0.93	1.14	16.18**
11	0.77	1.08	0.65	0.46	13.41*
12	0.72	1.01	2.42	0.10	33.45****
13	0.78	1.36	1.36	1.46	21.65**
14	2.72	2.83	4.86	6.82	8.80
15	2.58	3.93	1.36	1.66	24.68***
16	0.69	2.59	1.06	0.0	29.61****
17	0.45	1.33	1.02	2.29	10.17
18	0.87	1.24	1.06	0.75	28.05****
19	1.34	0.85	1.3]	1.34	9.90
20	0.80	0.76	0.17	0.75	23.85****
21	0.80	0.85	2.44	0.24	38.45****
22	0.59	2.40	0.50	1.77	32.446
23	0.09	1.05	2.28	3.70	14.27*
24	0.72	0.59	2.20	4.04	25.21***
25	3.37	2.24	1.95	3.83	3.02

VARIANCE AND CHI SQUARE FOR PART B

		Family Varian	се		
Statement	Ministers N=42	Psychologists Psychiatrists N=39	Doctors N=25	Survivors N=34	χ ² Values
26	0.93	0.90	0.83	0.10	10.75

1.00

1.15

2.07

TABLE VII (Continued)

* = <u>P</u> < .05 ** = <u>P</u> < .01 *** = <u>P</u> < .001

**** = <u>P</u> < .0001

0.55

2.49

2.00

27

28

29

49

6.14

63.60****

51.12****

0.63

0.0

1.23

0.49

0.63

0.37

TABLE VIII

	Mean of Variance		
Group	Part A	Part B	
Ministers	0.99	0.98	
Survivors	2.02	1.92	
Psychologists & Psychiatrists	1.42	1.00	
Doctors	2.67	1.60	

COMPUTED MEAN VARIANCE FOR EACH INDIVIDUAL GROUP OVER PART A FOR THE PATIENT AND PART B FOR THE FAMILY*

*Data from Table VI

The survivors statements dealing with methods for the family also covered several areas. The five statements having the greatest variance

are:

- Patients should not be kept alive under artificial methods but be left the dignity of a human being. (6.82)
- Help the family through counseling sessions to articulate their feelings and help them develop as supportive relationship with the patient as possible to facilitate his needs. (4.35)
- Aid the family so they will avoid putting their own emotional problems on the patient. (4.12)
- Give the family some reading therapy, suggestions, Ross's On Death and Dying, Moody's Life After Life. (4.10)
- Hospitals should offer in their services a qualified counselor that the patient or the family might use if they so desire. (4.04)

Research Question Number Four

Is there a significant difference between the groups' responses?

In order to find if the groups differed significantly in the way the statements were ranked, the investigator ran a Chi Square Test on each individual statement. The results are shown in Tables VI and VII. In Part A of the opinionnaire which deals with methods for the terminally ill patient. The groups differed significantly on twenty-four of the twenty-five generated statements. Statement number two was the only statement, which all the populations did not rank differently.

Following is a discussion of the statements from Part A, which the four groups ranked at a significant difference. The data indicated the rankings differed at various levels of significance.

Statements 1, 12, 10, 4, 15 and 25 all were significant at $\underline{P} < .05$ level. In the statements at this level of significance, the survivors had the greatest amount of variance in the ranking of the statements, while the ministers ranked their statements with the second highest degree of variance.

The next group of statements were significant at the <u>P</u> < .01 level. These statements included numbers 11, 17 and 22. The survivors were again the highest in ranking the statements with variance, with the doctors being second highest in variance.

At the significance level of $\underline{P} < .001$ there were two statements, numbers 3 and 9. In statement number 3 the survivors had the most variance in their rankings, with the doctors having the second highest amount of variance. Statement 9 data reveals the psychologistpsychiatrist group with the most variance while the **do**ctor population were again second highest in variance.

The following statements 5, 6, 7, 8, 13, 14, 16, 18, 19, 20, 21, 22, and 23 were significant at the <u>P</u> < .0001 level. In this complete

51.

group of statements the survivors reveal the most variance in their rankings and the doctors were again second high in their rankings with variance.

There are thirteen statements which fall in this significance level <u>P</u> < .0001. From these statements, the ideas and views expressed were very diversified. Due to the many different expressions of concern falling at this level, the following is a brief paraphrasing of the statements:

- Help the patients talk out their feelings, by being an authentic person.
- Patients don't have to act special to please others.
- Patients need a high degree of emotional interaction.
- One should not be overly nice or pamper the patient, causing them to feel less than human.
- Professionals working with patients need to express a mood of security.
- Develop an inner listening ear, to hear feelings.
- Patients should be allowed to make choices or options as it is their lives.
- Let patients know you love them and God loves them.
- Don't approach the terminally ill with a miracle attitude.
- There is a need for information concerning medical care.
- Young terminally ill need information about financial aid.
- Hospitals need a qualified counselor.
- Professionals need knowledge of patients' background to stimulate memories of happier days.

On all of the 24 statements concerning patients which were ranked significantly different, the data reveals the survivors ranked the statements as being most important the greatest number of times, while ministers were the second group to rank most important. The doctors ranked the statements as being least important most frequently.

Following is a discussion of the significant differences in the group rankings, for Part B, methods to aid the family. From this part

of the opinionnaire there were 23 out of the 29 generated statements, that data indicated are ranked significantly different. Again the computed results show that the statements differ at various levels of significance.

Statements 11 and 23 were significant at \underline{P} < .05 level. Psychologists-psychiatrists ranked statement 11 with the greatest amount of variance, while on statement 23 the survivors rankings varied the most.

At the level \underline{P} < .01 statement 10 and 13 were significant. The survivors rankings indicated the highest degree of variance on both statements.

Statements 3, 4, 7, 8, 15 and 24 were significant at \underline{P} < .001 level. On this group of statements the survivors had the greatest amount of variance, while doctors were second in the variance among their rankings.

At the significant level $\underline{P} < .0001$, the data indicates the following statements were significant; statements 1, 2, 5, 6, 9, 12, 16, 18, 20, 21, 22, 28, and 29. The survivors were the group which varied the most overall as they ranked the statements. The psychologistpsychiatrists group had the second highest degree of variance in their rankings.

The statements of the \underline{P} < .0001 level of significance for family members also numbered thirteen. In the statements, again is found a wide variety of concepts, as well as some of the views that were expressed by the statements at this level for the patients. Following is a brief paraphrasing of these thirteen statements:

Suggest reading therapy for the family.

• Be an empathic listener.

53.

- Aid the family, to avoid putting their own emotional problems on the patient.
- Help the family accept death.
- Help the family deal with guilt feelings.
- Discuss the level of awareness of the disease and perceptions with family members.
- Assure the family God does give the ability to handle any situation.
- Support and help can come from friends who come and allow the family some free time.
- Information about financial aid for the young terminal patient is needed.
- Families need to be prepared and have support in helping them deal with the disfigurement that may come to the loved one.
- In large hospitals families need a service that will give support and explain procedures.
- Families should keep patients from feeling they are becoming a financial burden.
- Insist on family participation in helpful chores around the sick room.

On all of 23 statements which were significant ranked different

at the various levels of significance, the data results shows that the ministers choose the statements to be classed as a most important statement the greatest percent of the time, while the psychologistspsychitrists were very close in their percentage as the statements being in the top category. The doctors choose the least important position for the statements the highest percent of the time.

CHAPTER V

FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

Summary

While there has been some increase in reported research dealing with death and bereavement (Weisman, 1972), studies have been lacking in dealing directly with the terminally ill patient. Even less has been done in working to help meet the needs of the family of the terminally ill patient. The major purpose of this study, therefore, was to investigate the perceptions of methods of helping terminally ill patients and their families among these four groups: ministers, doctors, psychologists and psychiatrists and survivors of terminally ill patients. The investigator used a modified Delphi Method to find out what perceived methods these groups might have and how the various groups would rank these opinions. To obtain concrete methods from the four groups, three experts from each of the four populations were interviewed and asked to state methods they felt would be most helpful to the terminally ill patients and their families. These statements were then developed into an opinionnaire which was mailed to a random sample of 60 participants in each of the four populations. The population thus consisted of 240 individuals. There was a 70% return from the ministers, 65% from the psychologists and psychiatrists, 42% from the doctors and 57% from the survivors, giving a total of 140 returns.

The sample was randomly selected, by the investigator using the six congressional voting districts to divide the state, so there would be an equal representation of both rural and urban populations.

The names of the participants for the three populations of doctors, ministers, and psychologists and psychiatrists were randomly chosen from the telephone directory in the designated areas. The names of survivors were compiled from the obituary notices in the Oklahoma newspapers.

Percentages and frequencies were used to determine the top tenranked statements. The variance of each item was calculated to determine if the populations had variance within their own groups rankings. The Chi Square Test was used to examine the difference between the rankings of the groups.

Results

The top statements for the patients indicated that the populations felt the patients needed much support and help in dealing with basic emotional needs by learning to talk about their situation and by people involved in their lives and their care helping them not feel abandoned by verbal and non-verbal communication. The statements also dealt with the patient having the right to know and understand the effects of some medical treatments, and be allowed to make their own choices.

There also was a consensus that the patients need to know God loves them and gives strength to face the situation. The ten methods for the family dealt with the family also having emotional needs and required support, and the need to have help in talking about their own feelings. They also chose methods that helped the family deal with and

better understand the emotional adjustments of the patient in their family. There was a desire expressed that methods be used to keep accurate information about financial aid, services available, and the diagnosis and progress of the disease and effects on the patient.

The minister population had the least amount of variance as they ranked the methods, in both parts of the opinionnaire, for the patient, and for the family. The psychologists and psychiatrists were the next most consistent group in their rankings. The doctors varied the most in their rankings of methods to use in dealing with the patients. The survivors varied the most in their choices for methods to be used with the families.

The Chi Square Tests for each individual statement revealed that there was a significant difference in 24 out of 25 of the methods that were suggested for the terminally ill patient. Twenty three statements out of 29 statements for methods to aid the family of the terminally ill were ranked significantly different by the four groups.

Conclusions

In the statement of the problem it was noted that 90% of all adult deaths in America are now the results of a terminal illness. The findings of the study indicate that within the chosen populations, those that are most involved in dealing with and handling this problem, have differences in their own feelings and beliefs. Thus it seems that patients and their families when going through the process of death, will come in contact with many different methods and ways of being treated. This would seem to complicate and confuse the already highly emotional and stressful situation. The patient and family often come

in contact with many different doctors and also ministers as they strive to combat disease. From the findings it seems apparent that the patient and their families might become accustomed to or expect a certain behavior, then be forced to change to a different specialist and find a totally different manner of being treated. It is also obvious that the survivors have had different experiences, as their rankings showed the most variance on methods to help the family. All of these findings point to the fact that there is still little being done to give consistent aid to patients and families, possibly due to the very different training or backgrounds of the populations involved.

Implications

As people often express a feeling of insecurity when terminal illness strikes--both in the lives of others and in their own lives-there may be merit in communicating the findings and implications of studies such as this one to as broad an audience as possible. The information gained from such research might be presented in the following ways:

- The mass media, articles in popular magazines, or news releases and columns in newspapers, as well as the use of radio and television.
- 2. The formal education system, including classes and seminars on the secondary and college levels, dealing not only with the topic of death, but on the emotional feelings and wants as well as aids to better help understanding terminally ill people as well as their families.

3. Community wide projects such as workshops and seminars.

It is important that the professionals most closely associated with helping the terminally ill and their families be aware of any information that might help them in their effort. Information gleaned from studies such as this one could be disseminated to the professionals in the following ways:

- 1. Publication of articles in professional journals.
- The formal education system, involving the educational programs for ministers, doctors and psychologists and psychiatrists as well as other helping professions.
- Workshops and seminars for those professionals who have completed their education and are working in their respective fields.

Recommendations

Recommendations for further study are:

- Further investigation might be conducted with a sample composed of terminally ill patients.
- The research might be replicated on a nationwide basis, to determine geographic differences.
- Additional examination of the clergy would be beneficial in order to determine if various beliefs and characteristics would be affected by one's membership in particular denominational groups.
- 4. Further research into the doctors backgrounds such as age, to see if training differed, the differences in training of M.D.'s and D.O.'s, family physician to that of a surgeon, to see if these factors effect their methods and responses.

- 5. As research seems to indicate that the death and illness of a child as opposed to that of a mate might cause totally different reactions and needs, a study of survivors in these two groupings should be valuable for comparison and developing methods of aid for different situations.
- Further investigation conducted with a sample composed of nursing personnel.

A SELECTED BIBLIOGRAPHY

Aitken, Swan J. "Nursing the Late Cancer Patient." <u>Practitioner</u>, Vol. 183 (1959), pp. 29-33.

- Becker, Ernest. The Denial of Death. New York: Free Press, 1973.
- Berty, Ernest. "Strategy for Change." Charleston, WV: State Department of Education, 1972, ED 067732.
- Bureau of Statistics, U.S. Government Publication, Washington, DC, 1975.
- Carey, G. R. "Emotional Adjustment in Terminal Patients: A Quantitative Approach." <u>Counseling Psychologists</u>, Vol. 21 (Summer, 1974), pp. 742-746.
- Caughill, Rita, edit. <u>The Dying Patient: A Supportative Approach</u>. Boston: Little Brown, 1976.
- Crane, Diana. <u>The Sanctity of Social Life: Physicians Treatment of</u> <u>Critically III Patients</u>. New York: Russell Sage Foundation, 1975.

Cronk, H. M. "This Business of Dying." <u>Nursing Times</u> (August 31, 1972), pp. 33-38.

Cutter, Fred. Coming to Terms With Death: How to Face the Inevitable With Wisdom and Dignity. Westport, CT: Technomic Publishing Co., 1974.

- Cyphert, Fredick R. and Walter Grant. "The Delphi Technique: A Case Study." Phi Delta Kappan, Vol. 52, No. 5 (January, 1971),pp. 272-273.
- Dalkey, Norman C. <u>Predicting the Future</u>. Santa Monica, CA: The Rand Corporation, 1968.
- Dayton, Mitchell C. <u>The Design of Educational Experiments</u>. New York: McGraw Hill, 1970.
- Dempsy, David K. The Way We Die. New York: McMillan, 1975.
- Dennison, Dudley A. <u>Give It to Me Straight Doctor</u>. Grand Rapids, MI: Zondervan Publishing House, 1972.

Feifel, Herman. <u>New Meanings of Death</u>. New York: McGraw Hill, 1977.

Glaser, Barney G. and A. L. Strauss. <u>Awareness of Dying</u>. Chicago, IL: Aldine Publishing Co., 1969.

- Gubrium, Jaber F. Living and Dying at Murray Manor. New York: St. Martain's Press, 1975.
- Guello, S., J. Cherico and P. Shadick. <u>The Care of the Dying</u>. New York: McMillan Publishing Co., 1974.
- Helmer, Olaf. <u>The Delphi Technique and Educational Innovations:</u> <u>Inventing Education for the Future</u>. San Francisco: Chandler Publishing Co., 1967.

Hinton, John. Dying. Baltimore, MD: Penquin Books, 1972.

- Hopkins, J., P. Ritter and R. Stevens, edits. <u>Terminally II</u>. New York: McGraw Hill, 1969.
- Hunt, Gladys M. <u>Don't Be Afraid to Die</u>. Grand Rapids, MI: Zondervan Publishing House, 1971.
- Kalish, Richard. <u>Death and Ethnicity</u>. Los Angeles: Ethel Percy Andrus Gerontology Center, University of California, 1966.
- Kavanaugh, Robert E. Facing Death. Baltimore, MD: Penquin Books, 1974.

Keleman, Stanley. Living Your Dying. New York: Random House, 1974.

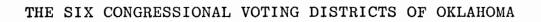
- Krant, Melvin J. <u>Dying and Dignity: The Meaning and Control of a</u> <u>Personal Death</u>. Springfield, IL: Thomas, 1974.
- Kubler-Ross, Elizabeth. <u>On Death and Dying</u>. New York: McMillan Publishing Co., 1969.
- Kubler-Ross, Elizabeth. <u>Death the Final Stage of Growth</u>. Englewood Cliffs, NJ: Prentice Hall, 1975.
- Lamerton, Richard. <u>Care of the Dying</u>. Westport, CT: Technomic Publishing Co., 1973.
- Lerner, Monroe. <u>Health Progress in the United States 1900-1960</u>: <u>A</u> <u>Report of Health Information</u>. Chicago, IL: University of Chicago Press, 1963.
- LeShan, L. L. "The World of the Patient in Severe Pain of Long Duration." <u>Journal of Chronic Diseases</u>, Vol. 17 (1974), pp. 107-115.
- Lifton, Jay and Eric Olson. Living and Dying. New York: Bantam Books, 1974.

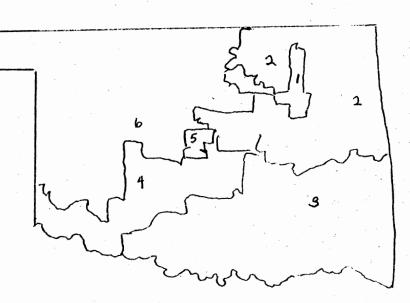
- McCoy, Marjorie. <u>To Die With Style</u>. Nashville, TN: Abingdon Press, 1974.
- Mannes, Marya. Last Rights. New York: Signit Books, 1973.
- Pfieffer, John. <u>New Look at Education</u>. New York: The Odyssey Press, 1968.
- Quint, Jeanne C. <u>The Nurse and the Dying Patient</u>. New York: McMillan Publishing Co., 1967.
- Schoenberg, Bernard. <u>Anticipatory Grief</u>. New York: Columbia University Press, 1974.
- Shepard, Martin. <u>Someone You Love Is Dying</u>. New York: Harmony Books, 1975.
- Shneidman, Edward. Deaths of Man. New York: Quardrangle, 1973.
- Shneidman, Edwin S. <u>Death: Current Perspectives</u>. Palo Alto, CA: Mayfield Publishing Co., 1976.
- Sudnow, David. Passing On. Englewood Cliffs, NJ: Prentice Hall, 1967.
- Taves, Isabella. Love Must Not Be Wasted: When Sorrow Comes Take It Gently by the Hand. New York: Crowell, 1974.
- Toynbee, Arnold. Man's Concern With Death. New York: McGraw Hill, 1968.
- Trombley, Lauren. "A Psychiatrists' Response to a Life-Threatening Illness." Death: Current Perspectives, Palo Alto, CA (1976), pp. 506-515.
- Troup, Stanley B. and William A. Greene, edits. <u>The Patient</u>, <u>Death</u> <u>and the Family</u>. New York: Scribiner, 1974.
- Weaver, Timothy W. "The Delphi Forecasting Method." <u>Phi Delta Kappon</u> (January, 1971), p. 52.
- Weaver, Timothy W. <u>Delphi A Critical Review</u>: <u>A Research Report</u>. New York: Syracuse University Research Corporation Report, 1972, ED 061636.
- Weisman, Avery D. "The Psychological Autopsy: A Study of the Terminal Phase of Life." <u>Community Mental Health Journal</u>, New York (March, 1968), pp. 63-74.
- Weisman, Avery D. <u>On Dying and Denying</u>. New York: Behavioral Publishing, 1974.

Whitman, Wayne and Loyd Lukes. "Guidelines for Using Behavior Modification With Terminal Patients." Journal of Nursing, 52 (May, 1974), pp. 106-113.

Zuehlke, A. and C. Watkins. "Measurements of Attitudes Toward Death." Journal of Chronic Disease, Vol. 22 (1975), pp. 406-414.

APPENDIX A





District	1		5	Counties
District	2		17	Counties
District	3	-	25	Counties
				Counties
District	5	-	1	County
District	6		27	Counties



District 1	5 Counties
Tulsa	331638
<u>District 2</u>	17 Counties
Bartlesville Miami Muskogee Talequah Sapulpa Wagner Vinita	29683 13880 37331 9254 15159 4959 5847
<u>District 3</u>	25 Counties
McAlester Duncan Ardmore Ada Durant Guthrie Holdenville	18802 19718 20881 14859 11118 9575 5181
District 4	10 Counties
Norman Lawton Shawnee Altus	52117 74470 25075 23302
District 5	1 County
Oklahoma City	366481
District 6	27 Counties
Beaver Guymon Stillwater Elk City Alva Enid Ponca City	1853 7674 31126 7323 7440 44088 25940

8

APPENDIX C

LIST OF AREAS AND NUMBERS FROM WHICH PSYCHOLOGISTS AND PSYCHIATRISTS WERE CHOSEN

Area	No.
Tulsa	17
Bartlesville	1
Muskogee	1
McAlester	1
Duncan	1
Ardmore	1
Norman	3
Lawton	2
Shawnee	. 2
Oklahoma City	17
Guymon	1
Stillwater	6
Enid	5
Ponca City	2



Below are statements generated by ministers, survivors of terminally ill, psychologists-psychiatrists, and physicians as their perceptions of methods that would be most helpful to the terminally ill and to their families. In order to establish a priority on the most useful methods, we would like to ask you to rate each statement on a 7-point continuum ranging from (1) which is the most important, to (7) which is least important.

EXAMPLE

Most Least Important Important

"Assist in the family facing this as a terminal illness"

(Please mark with an X)

METHODS FOR PATIENTS

- 1. Provide support during this time, as this is the greatest loss a person suffers, it cannot be modified and must be accepted.
- Feelings of anger and hate are often expressed in dying and counseling techniques would not alter this but accept it and help the patient vent these feelings.
- Help the person articulate about what they feel will happen to the family and to themselves after they die.
- Communicate through action and non-verbal behavior that the patient is not being abandoned at this moment in his life.
- 5. Help the patient talk out his situation, being authentic and real enough to accept and handle whatever the patient wants.
- People should not put arbitrary crap on how the patient should behave; you don't have to act special to suit me.
- Patients have a need for a high degree of emotional interaction from others; encourage friends and family to continue to come.
- 8. Develop an inner listening ear, to hear the patients real needs and not push your beliefs on them.
- 9. Let the patient and family know the church family is there, for strength or aid at any time.

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<u>///////</u> 1 2 3 4 5 6 7

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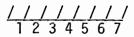
- Least Important
- 10. Try to talk to the patient and family together, so patient will feel there is a total honesty.
- Help the patient deal with any guilt he may have 11. about causing his condition (i.e., smoking, physical activity).
- The patient has the right to be aware of the side 12. effects that some medical treatments may cause, should have the option to say no to these treatments $\frac{1}{1234567}$
- 13. People should not be overly nice or pamper a patient because they are dying, causing them to feel less than human.
- 14. People working with terminal ill need to express some feeling or mood of security.
- Help patient find some hope, short term goals, 15. give them a sense of purpose, a reason to continue to function.
- Patient should have a choice in the options for 16. them, they should be allowed to make these decisions, as it is their life.
- 17. Patients should not just be kept alive under artificial methods but be left the dignity of a human being.
- 18. Let the patient know you love him and God loves him. That God made him an individual with the strength to face the situation.
- 19. Don't approach the terminally ill with a miracle attitude but pray that God's love flow through us.
- 20. There is a need for good advice about places for good medical care.
- 21. Young terminally ill patients and their families often need information about financial aid, as insurance won't cover the cost as medicare does for the elderly.
- 22. Hospitals should offer in their services a qualified counselor that the patient or the family might use if they so desired.

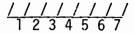
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- 23. Professions working with the patient should have knowledge of their background to stimulate their memory of by-gone happier days to console the ill.
- 24. Proper pain and nervous medication should be given to relieve anxiety and extreme stress conditions.
- 25. Make sure the clergy and church professionals make religion and death acceptable.

METHODS FOR FAMILY

- Give the family some reading therapy, suggestions Ross's <u>On</u> <u>Death</u> and <u>Dying</u>, Moody's <u>Life After Life</u>.
- 2. Be an empathy listener, respecting the existing crisis of the persons involved.
- 3. Help family work out how they should relate to the patient, offering a continuity of relationships.
- 4. Help the family through counseling session to articulate their feelings and help them develop as supportive relationship with the patient as possible to facilitate his needs.
- 5. Aid the family so they will avoid putting their own emotional problems on the patient.
- Help the family accept the finality of death and provide grief counseling before and after death.
- 7. Families need to remember and understand the patients are exposed to many strangers, who they must rely on for their needs and many unfamiliar medical practices.
- 8. Remember the patient's family are under stress and should be allowed to ask questions about expectations for the future.
- 9. Help the family deal with guilt they might experience, (i.e., if we'd have just brought him to the doctor early, etc.).

Most Least Important Important

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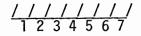
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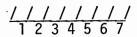
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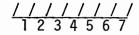


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Most Least Important Important

- 10. Discourage family from trying expensive unproven or quack medical cures.
- 11. Check to see if there is any unfinished business to deal with that professionals can help with (i.e., wills, financial issues).
- 12. Discuss with the family the level of awareness they have of the disease and what perception the family members have about what is going on. Encourage the family to talk to the doctor and get the facts.
- Encourage the family that just being there is as important to the needs of both the patient and to the family.
- Patients should not just be kept alive under artificial methods but be left the dignity of a human being.
- 15. Assure the family that God doesn't make any one suffer for their sins or the sins of others.
- 16. Assure the family God gives the ability to handle this situation.
- Remind the family that they must face responsibility of the rest of their lives and other family members, so they must take care of themselves also.
- 18. Much support and help can come from friends who set up with the patient giving the family some free time.
- 19. Young parents that are caring for small children when they must be at the hospital and can't afford to hire outside assistance, need some type of service or aid.
- Young terminally ill patients and their families often need information about financial aid, as insurance won't cover the cost as medicare does for the elderly.
- 21. Families need support and be prepared for the disfigurement that may occur to their loved one.

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- 22. In large hospitals where surgeons and specialists are so busy and thus impersonal, patients and families need a service that will give support and explain procedures.
- 23. When rural patients and families must go to larger hospitals out of their community, a service is needed that will enable them to feel they can leave the patient for a short time and also receive information about the city concerning lodging and eating establishments.
- 24. Hospitals should offer in their services a qualified counselor that the patient or the family might use if they so desire.
- 25. Make sure the clergy and church professionals make religion and death acceptable.
- 26. Keep family informed of diagnosis and progress.
- Insist on family being present and not make 27. them feel they are superfluous baggage.
- 28. Insist that the family should keep terminal patients from feeling they are creating financial problems.
- 29. Insist on family participation in helpful chores around the sick room.

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March 9, 1979

Dear Friend:

Due to the fact in Oklahoma alone in 1975, 24,854 people died with a terminal illness, as a professional person in a helping service, I see a need to establish some guidelines so we might be better prepared to be of useful service to the people who are ill and to their families.

These statements were generated by four groups: survivors of the terminally ill; psychologists and psychiatrists; ministers; and medical doctors. You have been selected to represent one of these groups and we would like to invite your participation. Your input is valuable and will be of great benefit in helping establish guidelines for aid. We are asking for only eight of ten minutes of your time in order to get an expression of your feelings.

Please fill these out anonymously and return in the envelope provided.

My sincere thanks to you for your input.

Sincerely,

La Nora Bloom



March 25, 1979

Dear Friend:

I am writing you regarding the questionnaire you received in the mail two weeks ago, concerning the terminally ill patient and their families. If you have already returned it, we thank you very much. If you have not completed it, we would encourage you to do so and return it in the postage paid envelope, as we feel your input will be most beneficial.

I appreciate your willingness to share your thoughts and feelings. We are hopeful we can establish some methods to be useful in aiding the terminally ill and their families.

Yours Sincerely,

La Nora Bloom

APPENDIX G

Frequencies-Percentages Distribution	
Variance Distribution	
Chi Square Values	
(Patients)	
(raciencs)	

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	Statement 1					State	ement 2		
	Min.	Psy.	Dr.	Surv.		Min.	Psy.	Dr.	Surv.
Most Important	39	36	20	34	Most Important	32	30	15	26
1-3	93%	93%	80%	100%	1-3	76%	78%	60%	76%
Neutral 4	0	0	0	0	Neutral 4	0	3 7%	5 20%	4 12%
Least Important	3	3	5	0	Least Important	10	6	5	4
5-7	7%	7%	20%		5-7	24%	15%	20%	12%
Total	42	39	25	34	Total	42	39	25	34
Variance	2.34	2.06	2.07	0.47	Variance	1.80	2.70	1.76	1.68
$x^2 = 8.02$			<u>P</u> <	.05	$x^2 = 10.35$			<u>P</u> >	.05

	Statement 3					Statement 4				
	Min.	Psy.	Dr.	Surv.		· • •	Min.	Psy.	Dr.	Surv.
Most Important	39	36	15	30		Most Important	36	33	25	30
1-3	93%	92%	60%	88%	· _	1-3	86%	85%	100%	88%
Neutral 4	7 3%	3 8%	5 20%	0	١	leutral 4	6 14%	3 7.5	0	0
Least	0	0	5	4	,	Least	0	3	0	4
Important 5-7	-		20%	12%		Important 5-7		7.5	%	12%
Total	42	39	25	34	1	[ota]	42	39	25	34
Variance	0.82	0.99	2.48	3.43	١	/ariance	0.98	2.38	0.56	3.43
$x^2 = 23.67$			<u>P</u> <	.001	>	$(^2 = 15.43)$			<u>P</u> <	.05

		State	ment	5		
	Min.	Psy.	Dr.	Surv.		
Most	39	39	20	25		
Important 1-3			20 25 % 80% 74% 5 0 20% 0 9 26% 25 34	74%		
Neutral 4	0	0	-	0		
Least	3	0	0	9		
Important 5-7	7			26%		
Total	42	39	25	34		
Variance	1.18	0.53	2.56	6.67		
$\chi^2 = 43.04$			<u>P</u> <	.0001		

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		Statement 6				
terretering a statement and a statement was	Min.	Psy.	Dr.	Surv.		
Most	28	21	15	21		
Important 1-3	67%	50%	60%	63%		
Neutral 4	11 26%	12 31%	0	0		
Least	3	6	10	13		
Important 5-7	7%	Psy. Dr. Si 21 15 5 50% 60% 6 12 0 6 31% 0 6 15% 40% 5 39 25 5 2.07 4.64 5	38%			
Total	42	39	25	34		
Variance	2.43	2.07	4.64	3.76		
$x^2 = 29.79$			<u>P</u> <	.0001		

	Statement 7					Statement 8			8	
	Min.	Psy.	Dr.	Surv.			Min.	Psy.	Dr.	Surv.
Most Important	39	30	10	34	•	Most Important	39	30	15	34
1-3	93%	77%	40%	100%		1-3	93%	77%	60%	100%
Neutral 4	0	6 15%	10 40%	0		Neutral 4	3 7%	9 23%	10 40%	0
Least	3	3	5	0		Least	0	0	0	0
Important 5-7	7%	8%	20%			Important 5-7				
Total	42	39	25	34		Total	42	39	25	34
Variance	2.53	1.82	1.84	0.47		Variance	0.68	1.56	2.80	0.10
$x^2 = 42.06$			<u>P</u> <	.0001		$x^2 = 21.40$			<u>P</u> <	.0001

		State	ment (9
	Min.	Psy.	Dr.	Surv.
Most	39	24 20		30
Important 1-3	93%	77%	80%	88%
Neutral 4	3 7%	6 15%	0	4 12%
Least	0	9	5	0
Important 5-7	93% 77% 3 6 7% 15% 0 9	23%	20%	
Total	42	39	25	34
Variance	0.68	4.36	3.76	0.94
$x^2 = 23.87$			<u>P</u> < .	.001

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		State	ment	10
	Min.	Psy.	Dr.	Surv.
Most	33	21	15	34
Important 1-3	79%	54%	60%	100%
Neutral 4	3 7%	9 23%	5 20%	0
Least	6	9	5	0
Important	14%	23%	20%	
Total	42	39	25	34
Variance	2.54	2.59	2.65	1.60
$x^2 = 14.59$			<u>P</u> <	. 05

			State	ment	11		_
	L	Min.	Psy.	Dr.	Surv.		Μ
	Most Important	32	30	10	26	Most Important	3
	1-3	76%	77%	40%	77%	1-3	8
	Neutral 4	7 17%	6 15%	5 20%	4 11.5%	Neutral 4	
	Least Important 5-7	3 7%	3 8%	10 40%	4 11.5%	Least Important 5-7	
		1 /0	0%	40%	11.5%	<u> </u>	
	Total	42	39	25	34	Total	4
	Variance	2.53	1.62	2.00	1.87	Variance	1
	$x^2 = 18.98$			<u>P</u> <	.01	$x^2 = 15.46$	

	Statement 11				
	Min.	Psy.	Dr.	Surv.	
Most	36	39	20	30	
Important 1-3	86%	100%	80%	88%	
Neutral 4	3 7%	0	0	0	
Least	3	0	5	4	
Important 5-7	7%		20%	12%	
Total	42	39	25	34	
/ariance	1.67	0.56	4.96	1.60	
$x^2 = 15.46$			<u>P</u> <	. 05	

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	Statement 13				
	Min.	Psy.	Dr.	Surv.	
Most	39	27	10	30	
Important 1-3	93%	69%	40%	88%	
Neutral 4	0	9 23%	15 60%	4 12%	
Least	3	3	0	0	
Important 5-7	7%	8%			
Total	42	39	25	34	
Variance	2.15	1.78	1.60	1.01	
$x^2 = 40.88$			<u>P</u> < .0001		

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		Statement 14			
	Min.	Psy.	Dr.	Surv.	
Most	28	27	5	34	
Important 1-3	67%	69%	20%	100%	
Neutral 4	11 26%	3 8%	10 40%	0	
Least	3	9	10	0	
Important 5-7	7%	23%	40%		
Total	42	39	25	34	
Variance	1.48	2.18	3.04	0.54	
$x^2 = .49.29$		<u>P</u> < .	.0001		

	Statement 15				
	Min.	Psy.	Dr.	Surv.	
Most	39	30	20	30	
Important 1-3	93%	77%	80%	88%	
Neutral 4	3 7%	6 15%	5 20%	0	
Least	0	3	0	4	
Important 5-7		8%		12%	
Total	42	39	25	34	
Variance	0.78	1.76	0.64	2.73	
$x^2 = 15.12$		<u>P</u> < .05			

		Statement 16			
	Min.	Psÿ.	Dr.	Surv.	
Most	42	36	20	25	
Important 1-3	100%	93%	80%	74%	
Neutral 4	0	3 7%	0	9 26%	
Least	0	0	5	0	
Important 5-7			20%		
Total	42	39	25	34	
Variance	0.43	0.85	5.44	1.66	
$x^2 = 43.25$			<u>P</u> < .0001		

		Statement 17			
	Min.	Psy.	Dr.	Surv.	
Most	32	33	20	25	
Important 1-3	76%	85%	80%	74%	
Neutral 4	7 17%	3 7.5%	0	0	
Least	3	3	5	9	
Important 5-7	7%	7.5%	20%	26%	
Total	42	39	25	34	
Variance	1.73	2.31	5.44	6.32	
$x^2 = 16.68$			<u>P</u> < .001		

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		Statement 18			
	Min.	Psy.	Dr.	Surv.	
Most Important	39	34	20	34	
1-3	93%	62%	80%	100%	
Neutral 4	3 7%	6 15%	0	0	
Least	0	9	5	0	
Important 5-7		23%	20%		
Total	42	39	25	34	
Variance	0.85	1.71	5.44	0.0	
$x^2 = 29.30$			<u>P</u> < .0001		

		State	ment	19				State	ment	20
	Min.	Psy.	Dr.	Surv.			Min.	Psy.	Dr.	Surv.
Most Important	42	15	15	25	Ĭ	Most mportant	22	30	15	34
1-3	100%	39%	60%	74%	_	1-3	53%	77%	60%	100%
Neutral 4	0	21 54%	5 20%	0	N	leutral 4	3 7%	6 18%	10 40%	0
Least	0	3	5	9		Least	17	3	0	0
Important 5-7		7%	20%	26%	1	mportant 5-7	40%	8%		
Total	42	39	25	34	T	otal	42	39	25	34
Variance	0.38	1.58	2.00	6.54	V	ariance	2. 78	1.48	1.84	3.11
$x^2 = 65.59$			<u>P</u> <	.0001	. X	$x^2 = 55.20$			<u>P</u> <	.0001

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		State	ment 2	21	
	Min.	Psy.	Dr.	Surv.	
Most	32	27	15	30	
Important 1-3	76%	69%	60%	88%	
Neutral 4	7 17%	3 8%	10 40%	0	
Least	3	9	0	4	
Important 5-7	7%	23%		12%	
Total	42	39	25	34	
Variance	0.93	5.05	1.20	3.51	
$x^2 = 27.28$			<u>P</u> < .0001		

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		<u>State</u>	ment 2	22
	Min.	Psy.	Dr.	Surv.
Most	25	30	10	26
Important 1-3	60%	77%	40%	76%
Neutral 4	11 26%	6 15%	5 20%	4 12%
Least	6	3	10	4
Important 5-7	14%	8%	49%	12%
Total	42	39	25	34
Variance	2.14	2.86	2.24	4.09
$x^2 = 17.37$		<u>P</u> < .01		

		Statement 23			
	Min.	Psy.	Dr.	Surv.	
Most	17	12	5	30	
Important 1-3	40%	29%	20%	88%	
Neutral 4	19 46%	6 15%	5 20%	0	
Least	6	21	15	4	
Important 5-7	14%	56%	60%	12%	
Total	42	39	25	34	
Variance	1.30	4.18	1.84	3.60	
$x^2 = 58.15$			<u>P</u> < .0001		

		Statement 24			
	Min.	Psy.	Dr.	Surv.	
Most	32	21	15	32	
Important 1-3	76%	54%	60%	94%	
Neutral 4	0	9 29%	0	0	
Least	10	9	10	2	
Important 5-7	24%	23%	40%	6%	
Total	42	39	25	34	
Variance	3.24	2.95	2.65	2.21	
$x^2 = 35.76$			<u>P</u> < .0001		

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		Statement 25					
	Min.	Psy.	Dr.	Surv.			
Most	30	27	15	25			
Important 1-3	72%	69%	60%	74%			
Neutral	3 7%	0	5 20%	0			
Least	9	12	5	9			
Important 5-7	21%	31%	20%	26%			
Total	42	39	25	34			
Variance	3.12	3.38	2.24	6.67			
$\chi^2 = 14.69$ <u>P</u> < .05							

(Family	1)

		State	ment	1			State	ment	2
	Min.	Psy.	Dr.	Surv.		Min.	Psy.	Dr.	
Most Important	31	30	10	26	Most Important	42	39	28	
1-3	74%	69%	40%	50%	1-3	100%	100%	80%	
Neutral 4	11 26%	6 15%	5 20%	4 25%	Neutral 4	0	0	5 20%	
Least	0	3	10	4	Least	0	0	0	
Important 5-7		8%	40%	25%	Important 5-7				
Total	42	39	25	34	Total	42	39	25	
Variance	0.59	1.78	1.36	4.10	Variance	0.37	0.0	1.36	
$x^2 = 27.92$			<u>P</u> <	.0001	$x^2 = 28.19$			<u>P</u> <	•

		State	ment :	3
	Min.	Psy.	Dr.	Surv.
Most	36	36	28	25
Important 1-3	86%	93%	80%	74%
Neutral 4	3 7%	3 7%	0	0
Least	3	0	5	9
Important 5-7	7%		20%	26%
Total	42	39	25	34
Variance	1.38	0.71	1.59	2.83
$x^2 = 17.83$			<u>P</u> <	.001

	<u>Statement</u> 4								
	Min.	Psy.	Dr.	Surv.					
Most	39	39	23	26					
Important 1-3	93%	100%	92%	76%					
Neutral 4	3 7%	0	0	0					
Least	0	0	2	8					
Important 5-7	· ·		8%	24%					
Total	42	39	25	34					
Variance	9.77	0.40	1.02	4.35					
$x^2 = 26.75$			P <	.001					

		Statement 5				
	Min.	Psy.	Dr.	Surv.		
Most	39	36	25	21		
Important 1-3	93%	93%	100%	62%		
Neutral 4	3 7%	0	0	9 26%		
Least	0	3	0	4		
Important 5-7		7%		12%		
Total	42	39	25	34		
Variance	0.58	1.17	0.56	4.12		
$x^2 = 28.60$			<u>P</u> <	.0001		

		Statement 6				
	Min.	Psy.	Dr.	Surv.		
Most	42	39	15	21		
Important 1-3	100%	100%	60%	62%		
Neutral 4	0	0	8 32%	0		
Least Important	0	0	2	13		
5-7			8%	38%		
Total	42	39	25	34		
Variance	0.36	0.18	1.42	4.07		
$x^2 = 75.90$			<u>P</u> <	.0001		

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	Statement 7					
	Min.	Psy.	Dr.	Surv.		
Most	35	18	15	26		
Important 1-3	83%	46%	16%	76%		
Neutral 4	7 17%	15 39%	10 40%	4 12%		
Least	0	6	. 0	4		
Important 5-7		15%	`	12%		
Total	42	39	25	34		
Variance	1.09	2.86	0.24	3.83		
$\chi^2 = 22.70$	-	-	<u>P</u> <	.001		

		Statement 8				
ана. 	Min.	Psy.	Dr.	Surv.		
Most	35	36	18	30		
Important 1-3	93%	93%	72%	88%		
Neutral 4	7 17%	3 7%	2 8%	4 12%		
Least Important 5-7	0	0	5 20%	0		
Total	42	39	25	34		
Variance	0.92	0.99	2.06	1.15		
$x^2 = 25.54$			<u>P</u> <	.001		

		Stat	ement 9	9			State	ment	10
	Min.	Psy.	Dr.	Surv.		Min.	Psy.	Dr.	Surv.
Most	39	39	25	21	Most Important	39	39	23	30
Important 1-3	93%	100%	100%	50%	1-3	93¢	100%	92%	88%
Neutral 4	3 7%	0	0	9 26%	Neutral 4	0	0	2 8%	0
Least Important	0	0	0	4	Least Important	3	0	0	4
5-7				12%	5-7	7%			12%
Total	42	39	25	34	Total	42	39	25	34
Variance	0.87	0.39	0.04	2.10	Variance	1.12	0.75	0.93	1.14
$x^2 = 34.55$			<u>P</u> <	.0001	$x^2 = 16.18$			<u>P</u> <	.01

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		State	ment	11			State	ment	12
	Min.	Psy.	Dr.	Surv.		Min.	Psy.	Dr.	Surv.
Most	39	36	23	34	Most	35	36	20	34
Important 1-3	93%	93%	92%	100%	Important 1-3	83%	93%	80%	100%
Neutral 4	0	3 7%	0	0	Neutral 4	7 17%	3 7%	0	· 0
Least	3	0	2	0.	Least	0	0	5	0
Important 5-7	7%		8%		Important 5-7			20%	
Total	42	39	25	34	Total	42	39	25	34
Variance	0.77	1.08	0.65	0.46	Variance	0.72	1.01	2.42	0.10
$\chi^2 = 13.41$			<u>P</u> <	.05	$x^2 = 33.45$			<u>P</u> <	.0001

		State	ment	13
	Min.	Psy.	Dr.	Surv.
Most	39	36	20	34
Important 1-3	93%	93%	80%	100%
Nuetral 4	3 7%	0	5 20%	0
Least Important 5-7	0	3 7%	0	0
Total	42	39	25	<u>,</u> 34
Variance	0.78	1.35	1.36	1.46
$x^2 = 21.65$			<u>P</u> < .	.01

		Statement 14				
	Min.	Psy.	Dr.	Surv.		
Most Important	36	30	20	21		
1–3	86%	77%	80%	62%		
Neutral 4	3 7%	3 8%	0	4 12%		
Least	3	6	5	9		
Important 5-7	7%	15%	20%	26%		
Total	42	39	25	34		
Variance	2.72	2.83	4.86	6.82		
$x^2 = 8.80$			P <	.05		

		State	ment	15
	Min.	Psy.	Dr.	Surv.
Most	33	30	15	30
Important 1-3	79%	77%	60%	88%
Neutral 4	3 7%	3 8%	10 40%	4 12%
Least	6	6	0	0
Important 5-7	14%	15%		
Total	42	39	25	34
Variance	2.58	3.93	1.36	1.66
$x^2 = 24.68$			<u>P</u> <	.001

		State	ment	16
	Min.	Psy.	Dr.	Surv.
Most	39	24	20	34
Important 1-3	93%	62%	80%	100%
Neutral 4	3 7%	6 15%	4 15%	0
Least	0	0 9 1		0
Important 5-7		23%	4%	
Total	42	39	25	34
Variance	0.69	2.59	1.06	0.0
$x^2 = 29.61$			<u>P</u> <	.0001

	Statement 17				State		ement 18			
	Min.	Psy.	Dr.	Surv.			Min.	Psy.	Dr.	Surv.
Most Important	39	30	20	26	•	Most Important	31	33	15	34
1-3	93%	77%	80%	76%		1-3	74%	85%	60%	100%
Neutral 4	3 7%	6 15%	5 20%	4 12%		Neutral 4	11 26%	3 7.5%	5 20%	0
Least Important	0	3	0	4		Least Important	0	3	5	0
5-7		8%		12%		5-7		7.5%	20%	
Total	42	39	25	34		Total	42	39	25	34
Variance	0.45	1.33	1.02	2.29		Variance	0.87	1.34	1.06	0.75
$x^2 = 10.17$			<u>P</u> >	. 05		$x^2 = 28.05$			<u>P</u> < ^	.0001

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		Statement 19			Statem			nent 20	
	Min.	Psy.	Dr.	Surv.		Min.	Psy.	Dr.	Surv.
Most Important	36	33	23	30	Most Important	42	39	20	34
1-3	86%	85%	92%	88%		100%	100%	80%	100%
Neutral 4	3 7%	6 15%	0	4 12%	Neutral 4	0	0	5 20%	0
Least Important 5-7	3 7%	0	2 8%	0	Least Important 5-7	0	0	0	0
5-7	1 10				5-7				
Total	42	39	25	34	Total	42	39	25	34
Variance	1.34	0.85	1.32	1.34	Variance	0.80	0.76	0.17	0.75
$\chi^2 = 9.90$			<u>P</u> >	.05	$x^2 = 23.85$			<u>P</u> <	.0001

	Statement 21		21			Statement			22	
	Min.	Psy.	Dr.	Surv.			Min.	Psy.	Dr.	Surv.
Most Important	39	39	15	34	•	Most Important	42	33	15	30
1-3	93%	100%	60%	100%		1-3	100%	85%	60%	88%
Neutral 4	3 7%	0	6 24%	0		Neutral 4	0	3 7.5%	10 40%	4 12%
Least Important 5-7	0	0	4 16%	0		Least Important 5-7	0	3 7.5%	0	0
Total	42	39	25	34		Total	42	39	25	34
Variance	0.80	0.85	2.44	0.24		Variance	0.59	2.40	0.50	1.77
$x^2 = 38.45$			<u>P</u> <	.0001		$x^2 = 32.45$			<u>P</u> <	.0001

		State	ment 2	23
	Min.	Psy.	Dr.	Surv.
Most	36	33	14	26
Important 1-3	86%	85%	56%	76%
Neutral 4	3 7%	6 15%	5 20%	4 12%
Least	3	0	6	4
Important 5-7	7%		24%	12%
Total	42	39	25	34
Variance	0.09	1.05	2.28	3.70
$x^2 = 14.27$		1	<u>P</u> < .	05

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		State	ment 2	24
	Min.	Psy.	Dr.	Surv.
Most Important	35	36	17	26
1-3	83%	93%	68%	76%
Neutral 4	7 17%	3 7%	3 12%	0
Least Important	0	0	5	8
5-7			20%	24%
Total	42	39	25	34
Variance	0.72	0.59	2.20	0.04
$x^2 = 25.21$			<u>P</u> < .	.001

		State	ment	25	
-	Min.	Psy.	Dr.	Surv.	
Most Important	28	30	17	26	Most Importar
1-3	66%	77%	68%	76%	1-3
Neutral 4	7 17%	3 8%	5 29%	4 12%	Neutral 4
Least Important	7	6	3	4	Least Importar
5-7	17%	15%	12%	12%	5-7
Total	42	39	25	34	Total
Variance	3.37	2.24	1.95	3.83	Variance
$x^2 = 3.02$			P >	.05	$x^2 = 10.$

		State	ment 2	26
	Min.	Psy.	Dr.	Surv.
Most	40	36	23	34
Important 1-3	93%	93%	92%	100%
Neutral 4	0	3 7%	2 8%	0
Least	2	0	0	0
Important 5-7	7%			
[ota]	42	39	25	34
/ariance	.0.93	0.90	0.83	0.10
$(^2 = 10.75)$			<u>P</u> > .	05

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		State	ment 2	27
	Min.	Psy.	Dr.	Surv.
Most Important 1-3	35	33	22	34
	83%	85%	88%	100%
Neutral 4	7 17%	6 15%	3 12%	0
Least Important 5-7	0	0	0	0
Total	42	39	25	34
Variance	0.55	1.00	0.49	0.63
$x^2 = 6.14$			<u>P</u> > .	.05

		State	ment :	28
	Min.	Psy.	Dr.	Surv.
Most	33	36	11	34
Important 1-3	79%	93%	44%	100%
Neutral 4	3 7%	0	14 56%	0
Least	6	3	0	0
Important 5-7	14%	7%		
Total	42	39	25	34
Variance	2.49	1.15	0.63	0.0
$x^2 = 63.60$			P < .	.0001

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		Statement 29			
	Min.	Psy.	Dr.	Surv.	
Most Important 1-3	25	27	2	30	
	60%	69%	8%	88%	
Neutral 4	7 17%	6 15.5%	18 72%	4 12%	
Least Important 5-7	10	6	5	0	
	23%	15.5%	20%		
Total	42	39	25	34	
Variance	2.00	2.07	0.37	1.23	
$x^2 = 51.12$			<u>P</u> < .0001		

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La Nora Gregory Bloom

Candidate for the Degree of

Doctor of Education

Thesis: A DELPHI STUDY TO DETERMINE METHODS TO AID THE TERMINALLY ILL PATIENTS AND THEIR FAMILIES

Major Field: Student Personnel and Guidance

Biographical:

Personal Data: Born in Beaver, Oklahoma, January 31, 1940, the daughter of Mr. and Mrs. Burl Gregory.

- Education: Graduated from Beaver High School, Beaver, Oklahoma, in 1958; received Bachelor of Science with major in speech education from Phillips University at Enid, Oklahoma, in 1962; received Master of Science degree in Student Personnel and Guidance from Oklahoma State University, in July, 1973; completed requirements for Doctor of Education degree at Oklahoma State University in July, 1979.
- Professional Experience: Teacher of language arts for Sapulpa Junior High School, Sapulpa, Oklahoma, from September, 1962 to June, 1964; teacher of speech for Enid High School, Enid, Oklahoma, from September, 1965 to June, 1969; halftime guidance counselor at Perkins High School, Perkins, Oklahoma, from September, 1972 to May, 1973; speech teacher at C. E. Donart High School, Stillwater, Oklahoma, from September, 1973 to June, 1974; Research Assistant for Occupational and Adult Education, in Career Education at Oklahoma State University, from September, 1975 to May, 1976; Elementary Counselor for Cushing Public Schools, Cushing, Oklahoma, from August, 1977 to May, 1978.
- Other Professional Experience: Owner and operator of two children's clothing stores in Enid, Oklahoma, from May, 1969 to May, 1971; Education Director for Christ United Methodist Church in Enid, Oklahoma, from August, 1978 to April, 1979.

- Professional Organizations: American Personnel and Guidance Association, Oklahoma Personnel and Guidance Association, National Educational Association, Oklahoma Educational Association, Member of Phi Delta Kappa, Member of Honorary Speech Organization.
- Publications: Briggs, Lloyd and Bloom, La Nora. <u>Career</u> <u>Education Resources for Educational Personal Development</u>, an annotated bibliography, Oklahoma State University, Stillwater, Oklahoma, 1975.