THE EFFECT OF MEDICAL PROFESSIONALS' ATTITUDES ABOUT MORTALITY ON THEIR COMMUNICATION WITH THE TERMINALLY ILL

By

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Charles Richard Farrell, Sr.
March 2, 1912 - March 6, 1981
"...until we meet again."
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A work of this proportion is never a singular effort. It requires the time and effort of many people. I am grateful that these people had the time for me. In working with them I have learned the most valuable lessons of all.

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ABSTRACT

This study investigated how medical professionals' attitudes about mortality affect communication with the terminally ill. A questionnaire was administered in an attempt to verify the factors identified in the literature which affect communication between the medical professional and the terminal patient. Statistical analyses were also performed on the data. The results were interpreted in light of ethnographic observations made on a palliative care unit (cancer ward) over a five week period.

Findings indicated that attitudes about mortality moderately but significantly affect the tenseness felt in communication with the terminally ill. In actual communication this tenseness affects the comfort, directness and effectiveness evinced in the medical professional/patient dyad. The results also indicated that attitudes about mortality slightly influenced viewing the terminally ill as different from other patients, but that this has little effect on tenseness felt in communication.
CHAPTER I

INTRODUCTION

"I am not afraid to die, I'm just afraid of what will happen to me between now and then." -- Charles Farrell in conversation. January, 1981.

The topic of death is unsettling at best, probably because few of us want to think about dying. Thus, as a society we deny, delay and try to disguise our own mortality. As Elizabeth Kubler-Ross (1969, p.7) explains:

We use euphemisms, we make the dead look as if they were asleep, we ship children off to protect them from the anxiety and turmoil around the house if the patient is fortunate enough to die at home, we don't allow children to visit their dying parents in the hospitals, and we have long and controversial discussions about whether the patient should be told the truth.

We are, in short, uncomfortable with death and the process of dying; we are awkward in its presence. The process of dying changes the condition of existence, it alters the context of life. This change is pervasive. The process is physically and psychologically manifested in not only the person who is dying, but in the family, friends, and attending medical professionals as well. And, although we attempt to "keep things as normal as possible", the fact is that most
people don't view death as "normal", but as an interruption of that which is "normal". Thus it is indeed difficult to view the dying, as Sandal Stoddard (1978, p. 28) suggests, "...as persons, and as individuals accomplishing an important part of a full life cycle..."

The implications of dying for communication are complex and ubiquitous. The process of dying changes the context of existence, and thus alters the context of communication. Thus, it would seem that in order to understand, or at least confront the ramifications of this change, we would need to confront our own mortality. If we are to attempt to understand how dying might affect our communication, we must first become aware of our own feelings about dying.

In the field of medicine this awareness is crucial. Often times the responsibility of communicating with the patient rests entirely on the shoulders of the medical staff. Families may find themselves unable to cope with the patient's illness, and thus will limit contact. As a result, the medical professional may become the person to whom the dying patient talks most often. Thus, it is important that medical professionals feel comfortable in this position. But in order to feel comfortable with a dying person, medical professionals need to be comfortable with death in general, especially their own. It would seem that comfort with personal mortality is paramount to comfort in communication with the dying.
However, the unfortunate truth in this situation is that medical professionals are prone to the same uneasiness with personal mortality that we all are. It cannot be assumed that, because a person is trained as a doctor or nurse, they have also been trained to abandon their human attitudes about death. In an effort to improve communication between medical professionals and the terminally ill, this thesis will attempt to determine the effects of medical professionals' feelings about mortality on their communication with the terminally ill.

In order to understand the effects of attitudes about mortality on communication with the dying, the attitudes themselves need to be determined. To accomplish this, three main steps will be taken: first, we will examine how attitudes have changed historically; second, we will investigate the psychological and sociological contexts of death; and finally, we will examine current practices surrounding death. Both a historical and literary perspective will be taken to help establish the context of mortality. This discussion will be followed by a review of pertinent literature, and presentation of the research question and rationale.

**Historical and Literary Perspectives on Death**

A complete historical and literary review of attitudes toward death is not possible here, nor is it the
focus of the study. But examining the prevailing attitudes which have formed over the years may allow us to understand the foundations of some of our currently held attitudes. At the very least, being familiar with past attitudes can only enrich our understanding of the context of death.

Notions about death have traditionally been reflected in the cultures that spawned them. For example, the ancient Greeks placed great emphasis on being physically fit and attractive. As a result, they practiced "exposing" of infants who were ill and unattractive; letting the infants die in order to insure that survivors were healthy and appealing (Stoddard, 1978). Similarly, a well-known hospital, Epidaurus, in the fifth century B.C. routinely refused to admit the terminally ill and dying on the grounds that they were a healing institution (Stoddard, p. 16, 1978). Both of these practices seem to indicate not so much a disregard for the human being as a denial of the sick and dying in the culture.

In marked contrast, the Roman Emperor Julian the Apostate in A.D. 361 ordered his followers to begin imitating the Christians in the care they showed the sick and the poor (Stoddard, p. 26, 1978). In addition, prior to A.D. 475 there was a hospice established in Turmanin in Syria, which served as a hotel-Dieu where pilgrims came to be refreshed, and the terminally ill to die (Stoddard, 1978). Clearly,
these examples indicate shifts in attitudes toward death—the growth of acceptance, and the waning of denial.

As is indicated by the previous examples, treatment of the dying has generally been approached with trepidation rather than enthusiasm—gingerly at best. In the thousand years between the Middle Ages and the twentieth century, attitudes toward death have shifted back and forth like a pendulum. Philippe Aries (1981) has suggested that during these years five models of death developed. The first model is labeled "the tame death"; a death that is under the control and direction of the dying person. He frequently reiterates the fact that the men and women of the Middle Ages did not refuse to acknowledge death, but accepted it and oft times orchestrated their final scene. In fact, he states that "Moralists and satirists made a point of ridiculing those unreasonable persons who refused to face facts and violated the natural order of things" (Aries, 1981, p. 9). The only death to be truly feared was the mors repentina or sudden death. It destroyed the order of the world in which everyone believed; "...it became the absurd instrument of chance, which was sometimes disguised as the wrath of God" (Aries, 1981, p. 10). Consequently, it was regarded as ignominious and shameful. These general attitudes toward death remained almost unchanged from approximately the fifth
century A.D. until the late thirteenth century. The view of death as a part of life was the popular view until the emergence of the second model, "the death of the self," in the late Middle Ages and Renaissance.

After the thirteenth century, death became clericalized. There was a growth in concern about the last judgement, and concealment of the corpse became the rule. Wills were introduced as instruments to secure prayers, as well as to divide property. The will, tomb, and epitaph became a person's biography. "Death of the self" is evident in each hallmark. The concern with an after life, the concealment of the body, the will-biography, the guarantee of prayers all suggest "a complex network that man has woven around himself the better to live and the better to survive death" (Aries, 1981, p. 201).

In some of the Shakespearean tragedies written between 1594 and 1610 the "death of the self" is clearly evident. Dying was characterized by the loss of all earthly possessions, and the slow process of decomposition as the future. There was a fear of the dead as evinced in Romeo and Juliet:

Or bid me go into a new-made grave
And hide me with a dead man in his shroud;
Things that to hear them told, have made me tremble;
And I will do it without fear or doubt.... (Act IV, Sc.1)

In Hamlet another peculiar aspect of dying is revealed, the idea of preparedness. This seems to be an echoing of
the mors repentina; a fear of dying suddenly with an unprepared soul. The ghost of Hamlet's father is doomed to walk the night because he was killed with "No reckoning made, but sent to my account, With all my imperfections on my head" (Act I, Sc. V). Similarly, in Macbeth untimely death becomes a hallmark of Elizabethan mortality. Again, an indication of a problem with the acceptance of death on death's terms:

She should have died hereafter; There would have been a time for such a word. To-morrow, and to-morrow, and to-morrow... (Act V, Sc. VI)

Through these brief examples we are provided some insight into the Elizabethan sensibilities of death. Death was represented by loss of earthly possessions as well as earthly appearance; fear of the unprepared death, the mors repentina; and finally, untimeliness. Death has become the ultimate loss of personal identity; a stark change indeed from the acceptance of the Middle Ages.

Aries describes the next three models of death as "death untamed." Up until this time death was understood and familiar even though it was not always graciously accepted. Death was a part of the natural order of things. With the advent of the untamed death, the process takes on an air of mysticism, surrealism, sorrow, and separation. Dying is now a process to be feared and, if possible, eluded. Aries explains the difference in the following excerpt:
we call (this) familiar death the tame death, we do not mean that it was once wild and that it was later domesticated. On the contrary, we mean that it has become wild today when it used to be tame. The tame death is the oldest death there is (p. 28).

The third model of death, "the remote and imminent death" of the seventeenth and eighteenth centuries, is the precursor of the twentieth century "invisible death." The disappearance of death is evident after the sixteenth century when documentation of the moment of death was abandoned by pious and scholarly writers. Similarly, death as life's final drama is ignored and treated as nothing extraordinary.

In the mid 1800's, Emily Dickinson expressed an amalgam of these attitudes toward death in her poem, "I heard a fly buzz when I died." In the poem she reveals an attitude of acceptance and control over the final drama reminiscent of the tame death; the family has been gathered around the deathbed and earthly possessions have been distributed. However, just as the scene is about to climax, a fly interposes "with blue, uncertain, stumbling buzz" (Dickinson, 1976, p. 262 C). Attention is thus diverted from the death of a person to an insignificant fly. Focusing attention on the fly emphasizes the banality of the death.

The remote and imminent death has become metaphysical in nature and is best expressed metaphorically as
"the separation of the soul and the body, which is like the separation of man and wife or of two old friends" (Aries, 1981, p. 300). The pain of death is like the sorrow of a broken friendship. Ultimately, the goal of this type of death is to "forget that death exists," and to die without "being aware of it" (Aries, 1981, p. 313).

The changes which occur in the nineteenth century introduce an unexpected view of death. The age of "the beautiful death" or "death of the other" is characterized by a sentimentalized death and domesticated heaven (Pike and Armstrong, 1980). Death has become the liberator, leading us out of a world of sin and sorrow and back to our domesticated haven in the sky (Aries, 1981). The loved one is memorialized in portrait and commemorative jewelry which serves as a substitute for the departed's physical presence (Aries, 1981). "In the nineteenth century everyone seems to believe in the continuation of the friendships of life after death" (Aries, 1981, p. 471). Death has become an avenue of escape from the hardships and indignities of this world.

This romanticized death of the nineteenth century quickly ebbed with the rise of industrialization and subsequent deterioration of the family and community as the cornerstone of society (Stannard, 1980). By the turn of the
century it was already being suggested that cemeteries be made more cheerful places, and funeral directors had begun practicing the newfound skill of concealment (Stannard, 1980). The age of the "invisible death" had arrived. This new style of dying has two basic characteristics. First, the "invisible death" is novel; totally contrary to everything preceding it (Aries, 1981). Second, the attitude changes accompanying this new type of death were sudden and rapid, which resulted in the switch to an invisible death requiring only one generation (Aries, 1981). Death has been taken out of the home and placed in the hospital where it can remain invisible (Aries, 1981; Kubler-Ross, 1969). Children are excluded from sharing in the death of a family member (Aries, 1981; Kubler-Ross, 1969). In addition, there is less concern with hell, but an increase in interest in an after life among the very ill (Aries, 1981).

An interesting aspect of the twentieth century treatment of death is the suppression of mourning. Outward displays of grief are not encouraged, and bereaved family members are urged to return to a "normal" pattern of daily living as soon as possible. According to Aries, "this is a way of denying the presence of death in practice, even if one accepts its reality in principle" (1981, p. 576). Not to be ignored, however, is a new trend currently being given
much attention in theory and practice—the hospice movement. Its focus is the "amelioration of the actual process of dying by restoring to the dying man his forgotten dignity" (Aries, 1981, p. 589).

Two themes in literature seem to dominate the period of the invisible death. The first is that person should not just "accept" death; dying is a battle between life and death. This view is eloquently championed by Dylan Thomas in "Do Not Go Gentle into That Good Night" (1939). The poem suggests that person should not willingly surrender to death, but fight the end of life. That, rather than be accepting of death, one should, "...not go gentle into that good night. Rage, rage against the dying of the light" (Thomas, 1939, p. 142). This poem embodies the spirit of denial of inevitable death that is characteristic of the twentieth century.

The second theme presented in the literature concerning death in the twentieth century is isolation. Leo Tolstoi in 1886 published "The Death of Ivan Illyitch," a short story chronicling the death of a 45-year old man from an undisclosed disease. This story introduces for the first time the "medicalized death" (Aries, 1981) of the twentieth century, and also reveals the numerous problems surrounding a lingering death (Aries, 1981; Tolstoi, 1886). The characters reveal many of the tendencies which are present in
our dealings with the dying today. Illyitch is dependent on his doctors for both diagnosis and treatment, and, as Aries suggests, his moods reflect the efficiency and effectiveness of his physician's decisions. The patient is trapped between acknowledging his disease and pain, and the anxiety that might be added by confiding his condition to someone else. He is forced to suffer alone, sentenced by lies that were originally designed to insure his and the family's peace-of-mind.

**Summary**

The purpose of this introduction was to investigate the context which mortality creates. In attempting to do this, we have examined how attitudes toward death have changed over the years. Although this survey was brief, a few conclusions concerning attitudes toward death can be drawn. First, it appears that we have not yet found a philosophy or definition of death with which we are comfortable. As a result, we remain awed and mystified by death, while at the same time remaining curious. Our attitude continually vacillates between fear, denial and acceptance. And, finally, when ignoring death does not work, we rationalize it, disguise it, or convince ourselves that it really is not "the end."
It is within this context that communication with the terminally ill and dying occurs. Because the changes that accompany terminal illness not only effect the patient, but those involved with the patient, as well, awareness of attitudes about mortality becomes crucial. Since our attitudes not only help create the context of communication, but also determine content, awareness of attitudes can provide greater insight and understanding of patients, families, and self. While we are interested in the effects of attitudes about mortality on communication in general, the specific focus in this study is medical professionals. Therefore the next step in this study will be to examine the specific attitudes of medical professional's toward death.

Review of Literature

Death as a topic for research and study has only recently been initiated. Research in the field has focused mainly on the problems of the dying rather than the problems of those who deal with the dying (Woodward, Gosnell, Reese, Coppola and Liebert, 1978; McIntosh, 1974; Kasch, 1981). A variety of programs designed to aid the dying have prospered (Lancet, 1967; Lancet, 1972; Krant, 1979; Kubler-Ross, 1969; Stoddard, 1978). The same is not true of research and studies designed to train those who help the dying to deal with their own mortality (McIntosh, 1974).
The indications that a problem exists in this area seem to be obvious. As Kubler-Ross (1964) discovered, physicians are often defensive about their terminal patients, and are unwilling to allow them to be interviewed. Some of this reluctance can be attributed to ethical concerns—patient confidentiality, invasion of privacy, and patient rights. However what Kubler-Ross encountered was not a calm, reasonable response to her request. Most physicians reacted with discomfort, annoyance, or overt or covert hostility. Thus, she felt that the intensity of the reaction was out of proportion to the request (Kubler-Ross, 1964). This observation seems to gain validity when viewed in light of research that has been done on medical professionals.

Backed by years of observation and empirical studies, experts in the field have indicated that both doctors and nurses are less than comfortable in their dealings with the dying (Davitz and Davitz, 1980; Airing, 1968; Krauss, 1978; Feifel, 1977; White, 1977; Benoliel, 1977; Garfield, 1977). Studies have shown that physicians fear death more than their patients do (Airing, 1968). In fact, denial of death by the patient is in direct proportion to the doctor's need for denial, and may even form the basis for the choice of medicine as a profession (Kubler-Ross, 1969; Airing, 1968; Garfield, 1977). It has been suggested that doctors need to deny death because its occurrence represents loss of control
over it, and their professional and technical limitations, as well. Experts have also observed that often times the choice of medicine as a profession is motivated by fear of death, and may actually be an attempt to control it (Airing, 1968; Garfield, 1977).

Compounding the medical professional's fear of death is the fact that they must decide how they will approach the death of a patient—the "cure vs. care" dilemma. The relationship between the patient and family hinges almost entirely on the position that the medical team assumes. If the cure approach is adopted, then the medical team assumes a position of hope until the last breath is drawn. If the care approach is chosen, critical evaluation of the patient's condition is the rule. While both positions have merit, experts have observed that the care approach is characterized by more trust, understanding and helping (Lippincott, 1933; Feifel, 1977; White, 1977; Garfield, 1977). The cure approach focus is more physiological, whereas the care approach is primarily psycho-social.

Some experts in the field have speculated that the choice of which approach is taken by the medical team seems to be a direct result not only of their training, but also of their personal feelings about death as well (Lippincott, 1933; Airing, 1968, Feifel, 1977). Traditionally, physicians are trained as "healers" and are ill-equipped to deal
with the "personal failure" of a patient's death (Feifel, 1977; White, 1979; Lippincott, 1933; Airing, 1968; Garfield, 1977). According to Feifel, "many of them (medical professionals) tend to use their professional knowledge as a buckler against unprotected encounter with death to bind their own anxieties" (p. 5. 1977). After years of observation, White does not find this practice surprising. He states that "in the process of caring for a patient some identification with his problem and personality may occur. To the physician engaged in such a dyad, the impending or threatened death of a patient may be even more of a threat than it might be to someone else, for the physician tends to have a greater fear of death than does the ordinary individual" (White, 1977, p. 93). Compounding the situation further, White has also observed that the death of a patient not only effects the physician on a personal level, but on the professional level as well. He states that patient death can "magnify feelings of impotence, ineptness and even guilt" (White, 1977, p. 94).

Unlike physicians, nurses are not faced with the responsibility of determining whether a patient will be diagnosed terminal. However, the nurse is the part of the medical team that will have the most patient contact after the diagnosis. As Benoliel (1978) points out, personal services to the dying are difficult at best, because
working with the dying patient does not afford the same satisfaction as that with patients who recover.

In a study conducted by Davitz and Davitz (1980) on nurses' reactions to patients' suffering, nurses described their response to death in terms of feelings of helplessness, depression, anger, and despair. They also indicated that witnessing death or working with a dying patient made them more aware of their own mortality (Davitz and Davitz, 1980). Furthermore, many reported that they avoided contact with a dying patient (Davitz and Davitz, 1980; Krauss, 1978).

Research Question and Rationale

Thus, from what has been supported by observation and empirical study, we can conclude the following: first, medical professional's may be afraid of death; second, the fundamental orientation of the medical professional--cure or care, may effect the relationship established with the patient; third, medical professionals may see death as a professional failure; and fourth, a dying patient may trigger feelings of helplessness, anger, depression, despair, and awareness of personal mortality in medical professionals. To examine the impact of these feelings on communication with the terminally ill, we will first look at how relationships are established and maintained through communication. Following this examination, the potential
effects of terminal illness on a relationship will be explored.

This study is investigating how medical professional's attitudes about mortality effect their communication with a terminal patient. But since attitudes are generally in a state of flux, asserting a strong relationship between any particular attitude and the resultant communicative behavior is difficult at best. In part, this study will attempt to demonstrate a relationship between attitudes about mortality and communicative behavior by examining what messages are sent and how these messages help structure and define relationships. That there is a relationship between communication and behavior has been suggested by the Palo Alto Mental Research Institute team of Watzlawick, Beavin and Jackson (1967). Although they look strictly at what messages are sent between people, their approach has been adapted to provide overall organizational guidelines. Discussion of attitudes and the why dimension of the medical professional patient interaction is an attempt to determine a relationship between attitudes and communication, but is not part of the Palo Alto perspective.

Watzlawick, Beavin, and Jackson (1967) in Pragmatics of Human Communication deal with "the behavioral effects of human communication" (p. 13). They view communication as strictly what messages are sent between people, and how these
communications structure and define their relationships.

Briefly, the pragmatic model of communication suggests that all communication has a content and relationship level; the content level is the verbal message which conveys information, and the relationship level is the behavior the information imposes. The later level, relationship, determines what sort of message it is to be taken as, and, therefore it determines the kind of relationship to be established. (Watzlawick et al., 1967, p. 52). How the parties involved define the relationship depends in part on how they punctuate a sequence of events—how they organize their interactions. Communicants set up patterns of interchanges that help them to organize "common and important interactional sequences" (Watzlawick, et al., 1967, p. 56). Through redundancy, a process of repetition, punctuated interchanges evolve into patterns of communication. These patterns of communication may be characterized as symmetrical or complementary, depending on whether the "relationships are based on equality or difference," respectively (Watzlawick et al., 1967, p. 68). In a symmetrical interchange partners tend to "mirror" each others behavior, while in a complementary interaction one partner's behavior supplements that of the other (Watzlawick et al., 1967). Finally, Watzlawick et al. suggest that the relationship is protected by homeostatic devices established by the parties. These devices allow for flexibility within
the relationship without jeopardizing the stability of the relationship. Homeostatic devices provide for "constancy within a defined range" (Watzlawick et al., 1967, p. 147).

One can only guess at the effect that terminal illness might have on this process of relationship building. The prior relationship--patterning, symmetry or complementarity, homeostatic devices, may all be destroyed, and the psychological trauma of being terminal may necessitate a complete restructuring of all relationships. Restructuring itself may be hampered by the amount of time the patient has left, not to mention the physical barriers which terminal illness may present. In relationships among family, friends, medical professionals and terminal patients, the effects of dying may be further compounded by the effects of personal attitudes about mortality. It is this last element, attitudes about mortality, that may have major implications for communication. Although the implications may apply to all people involved, our main focus here will be the medical professional.

A number of observations have been made which indicate that medical professionals' attitudes about mortality may affect the way they communicate with the terminally ill. Observations have indicated that the medical professional's fear of death may be expressed in terms of self-doubt or lack
of confidence (Airing, 1968, White, 1977). The effect of self doubt or lack of confidence on communication is a display of physical and/or mental uneasiness; the physical uneasiness is evinced by body posture and movement, and lack of physical and eye contact, and the mental uneasiness is evinced by disfluencies and filled pauses (McCroskey, Richmond, Daly, and Cox, 1977). Also, White (1977) has indicated that the medical professional's anxiety concerning death may or may not be accompanied by denial, but is most often accompanied by some masking of the truth concerning patient diagnosis, prognosis and condition. Thus, the medical professional is not always direct and open when communicating with a terminal patient.

Finally, it has been observed that many of the characteristics associated with high communication apprehension (McCroskey, 1977) have been observed in medical professionals who deal with the terminally ill. For example, McCroskey states that high communication apprehension is characterized by avoidance and/or withdrawal from communication. Davitz and Davitz (1980) concluded that nurses avoided contact with dying patients. Similarly, Dr. F. H. Epstein observed that doctors "hurried past" the beds of dying patients (Woodward et al., 1978). McCroskey (1977) also noted that highly apprehensive people were cool, independent, uncommunicative, disciplined, rational, hard-to-know, task oriented,
and businesslike. Feifer (1977) and White (1977) similarly observed that the "cure" professionals were usually more concerned with mastery, technique, and technology than human feelings. Finally, McCrosky (1977) associated high communication apprehension with negative interpersonal perceptions and negative expectations of future success. These attributes manifest themselves as anger, guilt and jealousy within the health care team of a terminal patient (Lippincott, 1933). Also, the physician who sees himself as a healer may not admit to the patient that there is nothing he can do, because of the negative implications of the prognosis.

Thus, it has been suggested by personal observation (Feifel, 1977; White, 1977; Garfield, 1977) that, when medical professionals interact with the terminally ill, their feelings about mortality affect the interaction. This has yet, however to be empirically tested. The following general theoretical model is offered as a summary and explanation of how these attitudes may affect this interaction.

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ATTITUDES OF DOCTORS AND NURSES ABOUT MORTALITY CAUSE FEELINGS OF ANXIETY RESULTING IN APPREHENSIVE BEHAVIORS CAUSING UNCERTAINTY IN COMMUNICATION WITH THE DYING
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This process can be summarized by stating that medical professionals become more aware of their own mortality when in the presence of a terminally ill person. The feelings of anxiety caused by the heightened awareness of personal mortal-
ity may result in anxious behavior. This anxious behavior may be manifested as lack of eye contact or lack of physical contact. It may also effect what messages are sent and how the patient/medical relationship is formed.

In addition to summarizing the observations of experts and empirical findings in the field, this theoretical model also provides a basis for testing the following research question:

How do medical professionals' attitudes about mortality effect their communication with the terminally ill?

In order to answer this question, a number of sub-questions will also be addressed. They are as follows:

S-Q 1: How do medical professionals view terminal patients?

S-Q 2: Do medical professionals perceive that they change the way they communicate with a patient because they are terminal?

S-Q 3: Do medical professionals perceive more tension, anxiety, or apprehension in their dealings with a patient because they are dying?

S-Q 4: Do medical professionals perceive that they have less physical contact or less eye-contact with a patient because they are dying?

S-Q 5: How do medical professionals view their own death?

S-Q 6: Does age, experience or exposure to terminal patients effect how medical professionals communicate with the terminally ill?

Sub-questions 1, 2, 3 and 5 are based on observations made in the literature that have not been empirically tested. Sub-question 4 focuses on physical contact and eye contact for two
reasons. First, it was felt that these two items could be easily observed and assessed by both the medical professional and the researcher. And second, both physical contact and eye contact are also considered reliable indicators of interpersonal attraction (Mehrabean, 1980). Finally, sub-question 6 was included to investigate whether repeated exposure to terminal patients could have an effect on communication.

This study will examine the effects of attitudes about mortality on communication with the terminally ill by examining the behavior of medical professionals who deal with the dying. That a problem exists in this area has already been established. How this problem manifests itself in communication is the object of this study.
CHAPTER TWO

METHODS

Research in communication with the dying is sparse, hence no single method of investigation has emerged as ideal. The development of appropriate methods has been hindered primarily by ethical considerations and limitations of empirical studies. Ethically, considerations of the principles of nonmaleficence, autonomy and veracity—doing no harm, individual rights, and truth-telling—have posed serious questions concerning research in the area of death and dying. The principle of nonmaleficence prompts considerations of inflicting harm, whether it be intentional harm or the risk of harm (Beauchamp and Childress, 1979). The prima facie duties of nonmaleficence prohibit intentional harm except in cases of self-defense, "while risking harm is allowed as long as the goals of the conduct are sufficiently important" (Beauchamp and Childress, 1979, p.99). Thus, researchers in the area must either present evidence that their research will not harm the patient, or that the goals of the research are paramount to patient risks. Considering the limited research that has been done in the area, supporting evidence for either of these positions is meager.
Patient autonomy and veracity foster considerations generally associated with patient confidentiality and patient rights. In cases where research deals with the terminally ill and dying the two primary issues are competence and disclosure of information (Beauchamp and Childress, 1979). In biomedical research there is concern about competence because "...certain physical and mental defects can result in a situation where patients and subjects are not—in psychological fact or law—able to give informed consent" (Beauchamp and Childress, 1979, p. 67). At this time investigation into the effects of terminal illness on personal competence are just beginning. Thus, judgements about the personal competence of terminal patients in order to gain informed consent are still difficult to ascertain.

The final ethical consideration, veracity, or disclosure of information, is governed by three considerations: first, what standards are being followed in the biomedical professions; second, what the reasonable person would want to know; and third, what individual patients or subjects of research want to know (Beauchamp and Childress, 1979, p. 71). In the past, a strong reliance was placed on the first standard. Currently, however, this position has been revised "...under the conviction that the doctor's proper role is that of acting in the patient's best medical interest..." (Beauchamp and Childress, 1979, p. 71). This translates
into medical care taking precedence over patient rights or research, and the ultimate decision concerning research resting in the hands of the attending physician.

These ethical responsibilities translate into three major research considerations. First, we must explain the importance of the research goals to medical professionals. Second, we must question medical professionals concerning the effect of particular illnesses on patient competence. And finally, we need to develop a working relationship with the attending physician(s), and the hospital staff. These ethical considerations, then, create certain boundaries which limit our method choices. Given the nature of these limitations, a combination of observational research and a pencil and paper measurement was chosen. The reasons for deciding on these methods requires some discussion.

There are three assumptions underlying the theory and research in this study. First, medical professionals generally fear death professionally and personally (Airing, 1968; White, 1977). Second, a relationship with a dying patient is difficult to achieve. And third, terminal illness creates a context within which relationships as we know them may not be possible. In part the nature of these assumptions helped determine which methods were appropriate for this study.
In response to the first assumption—that medical professionals generally fear death professionally and personally—a questionnaire was developed (see p. 31 for development). It was felt that the instrument must be non-threatening, and take a minimum amount of time to complete. The questionnaire format is familiar and therefore non-threatening to medical professionals who are already uncomfortable with the topic. Finally, the questionnaire provided a vehicle for validating personal observations. Responses of doctors and nurses could act as a check on the personal bias that occurs in observational research.

The second assumption, that a relationship with a dying patient is difficult to achieve, and the third assumption, that terminal illness creates a context within which relationships as we know them may not be possible, could not be examined with a pencil and paper instrument. These two aspects of the medical professional/patient relationship needed to be observed within the hospital setting. Therefore, ethnographic or participant observation was chosen as a second method. Ethnographic research is an anthropological method that allows the researcher to observe specific behaviors in their natural settings. In this study it would allow the researcher to study the communication between the medical professional and the patient within its context; to establish an understanding of the importance of this research among
observed medical professionals; and, to develop a better understanding of the role of the medical professional. Because the questionnaire focuses on the perceptions of one person, it cannot capture the nuances inherent in the relationship. However, personal observation can provide the contextual dimension necessary for evaluation. Additionally, ethical considerations are less confining when medical professionals have the opportunity to work with the researcher. Information concerning research goals and methods are openly discussed and, as a result, more trust exists between the two parties, and more freedom results for the investigator.

Finally, ethnographic observation was chosen to examine the context created by terminal illness and how medical professionals and patients establish relationships within this context. The importance of studying the context of this communication is obvious, as Bateson indicates:

People build experience into their whole philosophy of life; it will color all their future attitudes... Whenever they meet certain sorts of context, they will tend to see these contexts as structured on earlier familiar patterns (p. 164).

Since the context of communication created by terminal illness formed the cornerstone of this study, it was necessary to observe the context first hand. Ethnographic observation provides a vehicle which allows first-hand observation. In addition, beyond just observing the context of interactions, researchers claim that "...anthropological techniques may
gather information about human behavior that is impossible to obtain by the more quantitative methods" (Wilson, 1977, p. 246). They rationalize their positions based on two hypotheses. The first hypothesis, the naturalistic-ecological hypothesis, states that human behavior is significantly influenced by the settings in which it occurs (Wilson, 1977). It also claims that "...settings generate regularities in behavior that often transcend differences among individuals" (Wilson, 1977, p. 247). Thus, ethnographic observation can give us some insights into the patterns that may form in communication with the terminally ill. These patterns will be observable only in the natural context.

The second hypothesis, the qualitative-phenomenological hypothesis, asserts that "...social scientists cannot understand human behavior without understanding the framework within which the subjects interpret their thoughts, feelings and actions" (Wilson, 1977, p. 249). They argue that knowing the fact that certain feelings, thoughts, or actions exist is not enough. Researchers must know the framework within which they fit (Wilson, 1977). The one caveat that both perspectives impose on this method is suspension of the knowledge of prior research and theory "...until their experience with the research setting suggests its relevance" (Wilson, 1977, p. 251). Thus, in combination with the
quantifiable data that the questionnaire would yield, the ethnographic data would ensure a more complete understanding of the context which terminal illness creates for communication.

**Questionnaire**

The questionnaire, shown in Appendix A, was designed to yield quantifiable data on attitudes and perceived communicative patterns of medical professionals when dealing with the terminally ill. From the observations of experts in the literature, personal observations by the researcher, and the model described in Chapter 1, six variables concerning communication between the medical professional and the patient were identified. They were labeled as follows: tenseness, comfort, effectiveness, difference (seeing the terminal patient as different), mortality, and directness. Based on these variables, questions were developed to verify the observations of the experts, and the impact of terminal illness on how medical professionals communicate with terminal patients. The questionnaire was pre-tested by a group of student nurses with two years of clinical experience. The final form of the questionnaire was a seven position, bi-polar adjective scale on which participants were asked to check the position which they perceived corresponded to their practice with patients. The questionnaire was de-
signed to measure feelings about mortality and how they effect the way medical professionals view the terminally ill; how medical professionals perceive that they communicate with the terminally ill; and how medical professionals feel when they communicate with a terminal patient. Also, some demographic information was requested in order to determine the effect of experience, age, and position--doctor or nurse--on communication with the terminally ill.

Subjects

The instrument was distributed to the doctors and nurses on a palliative care unit--a unit composed of cancer patients who are no longer receiving curative treatment for their disease and who have six months or less to live--nurses at a metropolitan teaching hospital, and two groups of student nurses with previous clinical experience. Distribution of the questionnaire was limited to these groups for the following reasons: first, difficulty obtaining permission from hospital administrators to distribute the questionnaire; second, refusals, particularly by doctors, to participate in the study; and finally, a limited number of subjects who had exposure to terminally ill patients on a continuous basis. Subjects were told that the questionnaire was part of a study being done on communication with the terminally ill. Members of the palliative care unit
knew the questionnaire was part of a study which included being observed on the unit for five weeks. Each participant was asked to mark the position between the two adjectives that they perceived most closely corresponded to their actions. Subjects either received the questionnaire from the researcher or from someone asked by the researcher to distribute it. Since it was felt that knowing the specific purpose of the study might affect the answers of the subject, this information was not distributed. Ninety-five participants responded.

Coding and Data Analysis

The questionnaires were collected and separated into groups. Each group was labeled according to where the respondent worked—palliative care unit, general staff nurses on various units, student nurses on various units. Data were coded on a seven point scale; one was assigned to a positive position, descending to seven for a negative position.

After the information from the questionnaires was coded, a Pearson product-moment correlation was performed to see whether the items examining specific variables correlated. The items representing the variables were then summed to indicate an overall index for each variable.

The variables were then organized into a model representing how they are believed to interact with each other.
This model was based on the theoretical model presented in Chapter 1, and represents an expansion and labeling of the elements presented in the earlier model. This expanded model was then tested through a path analysis. The resulting path coefficients allowed a comparison of the relative effects of each independent variable on the dependent variables.

T-tests for related measures were done comparing items representing tension and anxiety with items representing effectiveness and directness in communication. Additionally, t-tests for independent measures were done comparing palliative care nurses to general staff nurses, and palliative care nurses to student nurses in order to test for the effects of exposure to terminal patients and experience on communication practices with the terminally ill.

Another series of Pearson product-moment correlations were performed to examine the relationship between ability to communicate and factors constituting tenseness, directness, effectiveness and anxiety within the following groups: palliative care doctors and nurses, general staff nurses and nursing students. Finally, two ANOVAS were performed to compare age groups on feelings about mortality.

Ethnographic Research

The second half of this study was composed of ob-
bservational research conducted for a five week period in a palliative care unit (PCU) of a metropolitan university hospital. The unit that was observed is an in-house hospice. It accepts only cancer patients for whom there is no longer any curative treatment available. Patients are admitted from within the hospital or referred from other institutions. The unit's primary goal is to keep the patients comfortable and pain-free.

Original plans had been to quantify the observational data. However, under the conditions in the PCU, it was not possible to observe patient/medical professional interactions in a way that could be measured in a standardized fashion. In addition, patient confidentiality, autonomy and privacy prevented controlled, systematic observation. Therefore, patient/medical professional interactions were observed during work rounds, interactions on the unit, consultation and assessment visits, home care visits, patient care conferences, and psycho-social care conferences.

Work rounds provided an opportunity to observe a group of medical professionals interacting with the patients, and with each other in the patient's presence. Interactions included patient/family, patient/medical professional, family/medical professional, and medical professional/medical professional interactions. Consultation and assess-
ment visits usually occurred outside the hospital. During these visits many patients were told that there was no longer any hope for cure. The patient, assessment nurse, the researcher and sometimes family members were present at these meetings. Home care visits usually involved the patient, home-care nurse, and the researcher. Generally, these were visits to check on the patient's condition. Patient-care conferences and psycho-social care conferences were meetings to discuss treatment, progress, and patient condition.

Informal interviews were conducted with members of the nursing staff and members of the allied health care team (i.e., coordinator of consultation and assessment, coordinator of home health care, coordinator of palliative care volunteers, coordinator of bereavement, social workers, and a professor of humanities in the medical school). These interviews focused on what role the individual played in the unit, why they decided to work with the terminally ill, and what special problems or considerations working with the terminally ill presented. Also, there was some discussion concerning personal feelings about death and communicating about death with a terminal patient.

Medical professionals were observed primarily to determine how their communication created relationships
with the dying patients. In addition, the nature of changes—physiological, psychological, sociological, and communicative, which accompany dying also was investigated. In essence, the observational research focused on the patient/medical professional dyad from the time the patient was assessed and admitted to the unit, up until his/her death. Careful attention was paid to the communication patterns established by the director of the unit, the residents, the interns, the primary care nurses, and the patients in interaction with each other.

Additionally, some observation was made of the adjacent oncology unit (cancer ward). Basically, the information gained was used in part to explain the differences in attitudes which existed between the members of the two units.

All observations were recorded in a journal with as little delay as possible. Doctor-patient interactions were observed during morning work rounds. Approximately 15 to 20 minutes was spent with each patient. Nurse-patient interactions were observed during breakfast, lunch and prior to shift changes. One doctor was observed for the entire five week period, with a resident and two interns being observed for three weeks and another resident and one intern being observed for two weeks. Seven palliative
care staff nurses were closely observed for five weeks, in addition to occasional observations made of nurses on other units and in other hospitals during consultation visits. During the five week period, the constant number of patients on the unit was ten. Six deaths occurred during the observation. An observation time summary chart is presented in Figure 2.1.

The researcher looked for evidence of accurate understanding of patient feelings, experience and behaviors as indicators of effectiveness, encouragement of patient to talk about concrete feelings eventually leading to self-disclosure as indicators of comfort, and genuineness of response, spontaneity and openness as indicators of directness. All observations were recorded to facilitate future analysis based on the pragmatic model of communication presented in Chapter 1.

**Subjects**

Observations were limited to members of the palliative care unit, the patients on this unit, and their families. Some limited observation of medical professionals and patients was conducted on the oncology unit. Also, some observations were made of my own family, and my father who was a patient on the PCU at an earlier time.
Figure 2.1
OBSERVATION TIME SUMMARY

<table>
<thead>
<tr>
<th>PERSON OBSERVED</th>
<th>WEEK 1</th>
<th>WEEK 2</th>
<th>WEEK 3</th>
<th>WEEK 4</th>
<th>WEEK 5</th>
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<td>DOCTOR 1</td>
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<td>RESIDENT 1</td>
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<td>INTERN 1</td>
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<td>INTERN 2</td>
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<tr>
<td>NURSES-OUTSIDE PCU intermittent observation throughout the 5 weeks.</td>
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</table>
This study examined the effects of medical professionals' attitudes about mortality on communication with the terminally ill. A questionnaire was designed to collect information on how well medical professionals perceive that they communicate with the terminally ill. The instrument also investigated feelings about personal mortality. In addition to this information, how communication was used to build relationships between medical professionals and terminal patients was observed for a five week period. After analysis, the data from the questionnaire were used as support for the ethnographic observations in an attempt to increase the validity of the findings.
CHAPTER THREE

EMPIRICAL RESULTS

This thesis was designed to investigate how medical professionals' attitudes about mortality effect the way they communicate with the terminally ill and dying. Since medical professionals are generally reported to feel less than comfortable with the terminally ill, it was believed that this predisposition could affect the way that they communicate. Within the following chapter the empirical results of this study are reported. All ethnographic observations will be reported in Chapter 4.

The results of the questionnaire were subjected to a series of statistical analyses. To check whether the items in the questionnaire correlated within the variables that they were designed to examine, a Pearson product-moment correlation was performed. The variables were then organized into a theoretically based model and tested through a series of regression analyses. In addition, to analyze the difference among groups, t-tests, and an ANOVA were done. Pearson product-moment correlations were also utilized to examine relationships between variables within subgroups of the sample.
Pearson Product-Moment Correlation Matrix

A Pearson product-moment correlation was performed to check whether items on the questionnaire that were designed to investigate specific variables correlated with other items investigating the same variable. The correlation matrix is presented in Table 3.1. The variable labels and the questions that correlated with them are listed below. These headings are followed by a brief description of the question content. The questions composing the variables are listed in Table 3.2.

Variable 1 - Tenseness (Questions - 7, 10, 12, 13)

Questions concerning tenseness when communicating with a terminally ill person, apprehensiveness when communicating with a dying person, avoidance of physical contact with a dying person, and avoidance of eye contact with a dying person were included for this variable.

Variable 2 - Comfort (Questions - 2, 3, 8)

This variable represented questions concerning comfort when talking about death with a terminal patient, unscheduled or unofficial visits with a terminal patient, and anxiety caused by the fact that the patient is dying.
Variable 3 - Effectiveness  (Questions - 4, 6, 14)

Questions concerning general communication skill, communication skill with a terminal patient, and amount of eye contact with "regular" patients as compared to terminal patients assessed for this variable.

Variable 4 - Difference  (Questions - 1, 5, 17)

Items questioning whether terminal patients are perceived as being different from other patients, the affect of terminal illness on communication with a patient, and whether terminal patients are communicated with differently were included here.

Variable 5 - Mortality  (Questions - 16, 18)

This variable was represented by two questions which asked about feelings concerning personal mortality.

Variable 6 - Directness  (Questions - 11, 15)

This final variable included questions concerning the effect of terminal illness on medical professional's self expression, and direct statements about patient condition.

Question 9, are you apt to take the death of a patient as a personal defeat, was included on the question-
### TABLE 3.1
PEARSON PRODUCT-MOMENT CORRELATIONS

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<thead>
<tr>
<th></th>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
<th>Q5</th>
<th>Q6</th>
<th>Q7</th>
<th>Q8</th>
<th>Q9</th>
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TABLE 3.1 (Cont.)
PEARSON PRODUCT-MOMENT CORRELATIONS

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<th>Q13</th>
<th>Q14</th>
<th>Q15</th>
<th>Q16</th>
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<th>Q18</th>
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<td>.1602</td>
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<td>.1919</td>
<td>.2020</td>
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<td>.1865</td>
<td>.0688</td>
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Table 3.2
Questions Composing Variables

Variable 1  Tenseness
  Q7:  Are you ever tense when talking with a dying person?
  Q10: Do you ever feel apprehensive when communicating with a dying person because they are dying?
  Q12: Do you ever avoid physical contact (non-medical) with a dying person?
  Q13: Have you ever found yourself avoiding eye contact with a dying person?

Variable 2  Comfort
  Q2:  Are you comfortable talking about death with a terminal patient?
  Q3:  How often do you just "visit with a terminal patient (on your own ward, not a family member)?
  Q8:  Does the fact that a person is dying make you anxious?

Variable 3  Effectiveness
  Q4:  How well do you feel you communicate?
  Q6:  Generally, do you feel you communicate effectively with a terminally ill person?
  Q14: Are you apt to have the same amount of eye contact with a dying patient as you would with a "regular" patient?
Variable 4  Different (Are terminal patients different?)
Q1: Do you consider terminal patients different from other patients?
Q5: Do you think that your ability to communicate effectively is apt to change when you talk to a dying person?
Q17: Does the fact that a patient is terminal change how you communicate with them?

Variable 5  Mortality
Q16: Are you apt to think about your own mortality when you deal with a terminally ill person?
Q18: Are you comfortable talking about your own death?

Variable 6  Directness
Q11: Are you ever unable to express yourself accurately when communicating with a dying person?
Q15: Do you avoid making direct statements to a dying patient about his/her condition?
naire to gain some insight into professional attitudes about mortality. It was not included to examine a specific variable.

The variables were then organized into a model representing how they are believed to interact with each other. This model was based on the general theoretical model presented in Chapter 1, and is actually an expansion of the same model. The model, presented in Figure 3.1, is an attempt to illustrate the effects of attitudes about mortality on how medical professionals view terminal patients, and the amount of tension felt in communication. The tenseness, which results from attitudes about mortality, and how medical professionals view terminal patients are thought to affect communication in terms of how comfortable, direct, and effective medical professionals perceived themselves to be when talking with a terminal patient.

Path Analysis

Following the development of this model (Figure 3.1), the items representing each variable were summed and the model was tested by a series of regression analyses. The resulting path (beta) weights, included in Figure 3.1, allowed comparison of the relative effect of each independent variable on the dependent variables. It was found that personal attitudes about mortality moderately but significantly affect how
A MODEL OF THE EFFECTS OF ATTITUDES ABOUT MORTALITY ON COMMUNICATION WITH THE TERMINALLY ILL

FIGURE 3.1
medical professionals treat the terminally ill, and how much tension they feel while communicating with the terminally ill. Likewise, the amount of tenseness felt in communicating with the dying moderately but significantly affects how direct and how effective communication is perceived to be. Tenseness also significantly affects how comfortable medical professionals are with the dying. Finally, it was discovered that viewing the terminally ill as different had only a slight effect on the amount of tension felt in communication with the terminally ill. A summary of the regression analyses is presented in Table 3.3.

T-Tests

In order to examine whether experience and exposure could have an effect on how medical professionals communicate with the terminally ill, the palliative care nurses—nurses who work only with terminal patients, were compared to general staff nurses and senior nursing students. It was felt that the former group would have less exposure to terminal patients and would therefore react differently from the palliative care nurses. The latter group, nursing students, was compared to the palliative care nurses to examine the implications of both exposure to and experience working with terminal patients. Lower scores indicated a positive position on the attitude scale whereas higher
### Table 3.3

**Regression Analyses**

<table>
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<tr>
<th>Dependent Variable</th>
<th>Independent Variable</th>
<th>$\beta$</th>
<th>SE($\beta$)</th>
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<th>Prob.</th>
<th>$R^2$</th>
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<td>.15494</td>
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</table>
scores indicated a negative position on the attitude scale.

The t-test results generally indicated that the palliative care nurses felt that they communicated well with terminal patients, while staff nurses and senior nursing students did not feel as confident. With regard to comparisons made between general staff nurses and palliative care nurses on question 12 ($t=-.33$, df=52, $p<.002$), the general staff nurses ($X=3.78$, S.D.=1.38, n=38) perceived themselves as being more tense while talking with a dying person than did the palliative care nurses ($X=2.44$, S.D.=1.32, n=16). Similarly, perceived accuracy of expression, question 16 ($t=-2.48$, df=52, $p<.03$), was less among general staff nurses ($X=4.95$, S.D.=1.61, n=38) than among palliative care nurses ($X=3.69$, S.D.=1.92, n=16). Although the differences between the two groups cannot be wholly attributed to exposure, constant contact could account for some of the perceived differences in communicative skills.

Question 11 ($t=-2.66$, df=37, $p<.012$), on effectiveness in communicating with the dying, yielded similar results for student nurses working within the hospital, but outside the palliative care unit. The palliative care nurses ($X=1.75$, S.D.=1.00, n=16) felt they communicated more effectively with terminal patients than did senior student nurses ($X=2.91$, S.D.=1.54, n=23). In addition, directness
in communication measured on question 20 (t=-4.29, df=37, p<.001), seemed to be more often a perceived characteristic of palliative care nurses (X̄=2.06, S.D.=1.44, n=16) rather than student nurses (X̄=3.96, S.D.=1.30, n=23). These results suggest that effectiveness and directness could be functions of years of experience working with patients and repeated exposure to terminally ill patients. Student nurses have both limited experience and exposure to terminal patients, thus these results were not surprising.

Experience and exposure seem to play an important role in the development of communication with the terminally ill. Although the role that attitudes about mortality plays is important, the effects of experience and exposure cannot be minimized. Based on an overview of the results, both exposure to and experience with terminal patients effects the perceived quality of communication. No other significant differences were noted.

**Pearson Product-Moment Correlations**

Pearson correlations were computed to measure the relationship between ability to communicate with the terminally ill and factors constituting tenseness, directness, effectiveness and anxiety within sub-groups of the sample. Only two significant correlations resulted. Among palliative care unit (PCU) doctors, there was a strong negative
relationship between perceived ability to communicate and physical contact with a terminal patient \((r=-.7430, \text{ df}=5, p=0.045)\). Within the same group there was a strong positive relationship between ability to communicate and perceived eye contact with a terminal patient \((r=.7593, \text{ df}=5, p=0.040)\).

Unlike PCU doctors, PCU nurses reported no significant relationships between ability to communicate and specific actions—eye contact, physical contact, etc.

**ANOVA**

Two analyses of variance were performed to compare age groups on feelings about mortality. Groups were divided according to the demographic information collected in the questionnaire. There were six age categories—under 20, 21 to 25, 26 to 30, 31 to 35, 36 to 40, and over 40. Questions 21 and 23 were the mortality variables. Results showed no difference between age groups on feelings about mortality. The means and the ANOVA summary table are presented in Tables 3.4 and 3.5.

**Summary**

This segment of this thesis examined the effect of attitudes about mortality on perceived communicative behaviors with the terminally ill. The data indicated that communication with the terminally ill is affected by
### Table 3.4

**ANOVA SUMMARY TABLE**

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<th>MS</th>
<th>F</th>
<th>P</th>
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<table>
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<th>df</th>
<th>MS</th>
<th>F</th>
<th>P</th>
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Table 3.5

MEANS

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<td>Group 4</td>
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<td>2.12</td>
<td>7</td>
<td>Group 5</td>
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<td>96</td>
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how we view the terminally ill, how well we perceive we communicate in general and the amount of tenseness felt in the presence of a terminal patient.

Experience with and exposure to terminal patients also influences our communication with the terminally ill. However, age differences do not influence feelings about mortality.
CHAPTER FOUR

ETHNOGRAPHIC RESULTS

The reasons for incorporating observational research within this study are numerous and varied. It was felt that in order to understand the impact of personal attitudes about mortality on communication with the terminally ill, it would be necessary to observe the context of interactions, and the formation and nature of the patient/ medical professional relationship. Also, the patient's condition and the training of the medical staff figure prominently in the development of communication, and thus were germane to this study. Finally, the effects of organizational structure and philosophy as they effect patient/ medical professional interactions warranted consideration.

As was stated in Chapter 1, the pragmatic perspective on communication developed by the Palo Alto Mental Research Institute (Wilder, 1979) supplied some of the overall organizational guidelines for this portion of the study. Original observations were based on Watzlawick's (1977) discussion of the content and relationship aspects of communication, and the role that these elements play in the defining of interpersonal relationships. In addition, Watzlawick's (1977) work concerning the effect of punctua-
tion—the ordering of sequences which results in the creation of different realities—structured the original planned observations. It was not until the ethnographic results were organized and analyzed that the entire pragmatic perspective was applied.

Context of Terminal Illness

The context which terminal illness creates is difficult to comprehend. As one nurse stated, "To empathize with a dying person is to admit that you will die." It is a state of isolation from which there is no escape. Patients use phrases such as, "...you don't understand...", "...how could you know how I feel...", "...I'm all alone...", indicating that even though they are still alive, they are somehow separated, set apart, different. This separation is enforced physically at times; that is, terminal patients are separated from other patients in the hospital either by unit designations, private rooms or curtains around their beds. It seemed to this researcher that even if the physical separation was not present that most terminal patients were already separated psychologically and physiologically from their loved ones and friends.

The psychological separation seems to occur after they have accepted the fact that they are dying. Accompanying the apparent loss of hope is puzzlement—what do I do now?
This bewilderment presents itself primarily nonverbally. Patients will occasionally stare off into the distance when a conversation is initiated. Others simply refuse to answer questions or discuss anything concerning their feelings or condition. Depending on how ill the patient is, he/she may refuse to communicate at all. Some of these behaviors can be attributed to medication and patient condition (pain, fatigue etc.). But, because this non-verbal behavior usually presented itself during the first few days on the unit, there is reason to associate it with the telling of the patient that there is no further curative treatment available. To exemplify, in a few cases where the researcher was present when a patient was told that his/her condition was not curable, the patient listened and seemed to understand what was being said. However, in subsequent conversations discussion of this information was ignored or met with a blank stare. Patients seemed to try to separate themselves from their physical condition by not communicating about it.

The physiological impact of terminal illness appeared slightly more obvious. As an example, one gentleman with a facial tumor refused to see certain members of his family and continually apologized for his appearance. He would often interrupt a conversation to ask if his appearance disturbed the speaker, or to comment on how horrible his appearance was. In another case, a young
woman, afflicted similarly, systematically announced who would be allowed to see her and when these same people would no longer be allowed to visit. Both patients determined their interactions with people based on the physiological progress of their disease.

The psychological and physiological changes which accompany any progressive terminal disease seem to create a new reality for the patient; a situation as new to them as it is foreign to those around them. The medical professionals who were able to establish and sustain a relationship with these patients seemed to share a perspective. They believed that what the patients were feeling was normal and acceptable under the circumstances. They recognized the effects of pain and fear on the character of the patients, and they appeared to be keenly aware of the impact of this disease (cancer) on patient behavior.

Organizational Context

Besides the context that terminal illness creates psychologically and physiologically, there is an organizational context created, as well. Within the hospital the palliative care nurses' station stands at the junction of two different wards--the palliative care unit and the oncology unit. Although both units deal strictly with cancer patients, their philosophies of care are radically different.
The palliative care unit's goal, as one unit nurse suggests, is "to help patients live the best they can, for the time they have left." Within this unit are cancer patients for whom all possible curative treatment had been exhausted. The unit is concerned with controlling the chronic pain that may accompany cancer in its final stages, and the psychological well-being and adjustment of both patient and family.

Immediately adjacent to the palliative care unit is the oncology unit. The oncology approach to cancer is aggressive treatment in the form of surgery, radiotherapy and/or chemotherapy with the hope of cure (remission). Patients on this unit were still receiving aggressive treatment for their cancer. Their philosophy is as long as there is life, there is hope.

Although the two units are not tied to each other, they are both under the supervision of the director of the division of oncology. It is within this relationship that philosophies clashed. The diverse opinions spawned by the opposing philosophies made communication between the two units less than satisfactory. This was compounded by the fact that the director of the two units was an oncologist who believed in aggressive treatment of cancer. Thus, the director's attitude was less than supportive of the work being done on the palliative care unit.
Because the medical professionals had to be careful about what they said concerning patients, occasionally patient interests took a back seat to organizational politics. For example, opportunities to move terminal patients to the palliative care unit were occasionally ignored in favor of keeping a "hopeless" patient on the oncology ward receiving treatment. Discussions concerning these patient placement decisions were fruitless, since both units were convinced that the patient should be with them. Differences of opinion like this one created a climate where all decisions were suspect.

For example, when two professionals disagreed on what course of action should be taken concerning the patient it was sometimes difficult to determine why they disagreed. Neither individual would clearly state their reasons for their decision. As a result communication between the two professionals was vague and subject to incorrect interpretation. The patients also suffered because they received conflicting, confusing or vague information from staff members who were not sure what decisions were being made concerning the patients' treatment.

Content and Relationship Dimensions

It is against the background created by the psychological and physiological effects of terminal illness
and the organizational aspects of the palliative care
and oncology units, that communication between the patients
and medical professionals was examined. The first changes
that followed a terminal diagnosis were the loss of inde-
pendence and the initiation of permanent and sustained
dependence on medical personnel. The nature and importance
of the content and relationship aspects of communication
changed radically at this point. To completely grasp the
impact of this change, a brief discussion of content and
relationship is necessary.

According to Watzlawick et al. "...any communication
implies a commitment and thereby defines the relationship"
(1967, p. 51). Thus, any information can structure our
relationship. Telling a patient that there is no longer any
curative treatment available can thus alter any previous
relationship. A patient who is given information on the
content level that they are dying, is left with pitifully
few behavioral responses. Previous patterned responses are
no longer meaningful. Even if the information is delivered
in the kindest manner, the problem of a response still exists.
Should the patient accept the prognosis, leave the room, and
begin dying? Or should they continue to hope, being fully
aware of the probable outcome? The content of the message
results in a relational dilemma.
Accompanying this relational dilemma is uncertainty. An unexpected visit, a change in medication, a peculiar expression on the face of a doctor or nurse can trigger panic. As a result, patients become hypervigilant—increasingly sensitive to the actions, movements, statements, and reactions of those people around them. Changes in routines are questioned; new faces are met with suspicion.

Most medical professionals concentrated on calming the immediate fears expressed by the patients. This frequently resulted in patients becoming leary of the professional's motivation. What seemed to be ignored was the fact that these patients were scared because they no longer had any control over their own existence. If they refused to do what was suggested, they had no alternative actions to choose from. There was no way out—you are going to die whether you take the directions of the staff or not. The only control granted was deciding whether you would die under hospital care or without it. After this decision was made, subsequent actions were automatic. If patients stayed in the hospital, they adhered to hospital rules and generally took directions from the hospital staff. Communicatively, this lack of control demonstrated itself in apathetic responses and occasionally distancing behavior. The staff generally took control in these situations by encouraging patients to communicate and talking to them as often as possible.
This situation placed medical professionals in a difficult position. While the patients initially looked on these relationships as savior and patient, the medical professionals looked on them as caregiver and patient. It was within the discrepancy caused by these conflicting relational views that communication became difficult and awkward.

Punctuation

The differing relational views seemed to be only a part of the problem between the patient and the medical professional. The hypervigilance evinced to varying degrees by all the patients observed resulted in continual misunderstandings. The misunderstandings usually surrounded the scheduling of home visits, or unpleasant treatments. If a doctor said, "We will try to make arrangements to send you home Thursday...", this is all the patient would hear. The patient would immediately block out the next sentence—"If this cannot be arranged, you will go home Monday." Consequently, the doctor was praised if the patient went home Thursday, or maligned if he/she went on Monday.

Doctors and nurses were periodically accused of lying, fibbing, or covering up something; particularly when a treatment failed, was painful, or unfeasible. Generally, it appeared that most of the patients were desperate to
stay alive, and this desperation altered their views of reality. In fact, all of the palliative care medical personnel struggled to be as honest and direct as possible with patients, without being painfully blunt. It was apparent to the author that at most of the assessment visits when patients were told that curative treatment was no longer available, that medical professionals dealt honestly with the information, whereas patients and families were not always capable of honest acceptance.

The ordering of events, the sequencing of episodes, allowed patients and families to occasionally avoid confronting reality. In fact, patients often could punctuate events and create different realities in the process. Often times if a patient's schedule of treatments was not changed after a set number of visits, both patient and family would take this as a sign that the patient was improving. In reality it could have meant just the opposite. The real difficulty arose when the medical professionals were not willing to be open about patient progress and allowed the patient and family to believe this "different" reality. In light of what has been observed by experts in the field, this lack of willingness to confront reality on the part of the medical professional is not surprising. As the literature suggests, it may represent their inability to deal with death or their unwillingness to deal with their own limitations.
Symmetry and Complementarity

The way that patients punctuated events seemed to indicate a need to exercise some control. In examining the types of relationships established, this lack of control becomes more obvious. Most of the relationships that were observed were complementary relationships with the patient in the one-down position. This is not surprising, considering the fact that all the patients were terminal, and were totally dependent on the medical staff. Symmetrical interactions between patients and medical professionals were rare. The unique twist that seemed to be caused by the nature of the situation was that, although the medical professionals were in the "one-up" position, they were not controlling the relationship as the patient thought they should—savior/patient vs. caregiver/patient. However, the patient was trapped because he/she was dependent medically and, therefore, remained in the "one-down" position.

For instance, the researcher was present once when a cancer patient visited his radiologist. After the prescribed number of radiation treatments the doctor asked to see the patient. It was clear to the researcher that the doctor was disappointed with the results of the radiation treatments. The patient only asked the doctor if they had
cured the cancer. The doctor tried to avoid answering the patient directly. However, the patient kept asking the same question. When no clear answer was given, the patient finally gave up and asked the doctor what they could do next. The patient attempted to gain control by pressing the doctor for an answer to his question. He was not willing to accept the answer the doctor gave him as a caregiver; he wanted the doctor to answer him as a savior. The patient refused to listen to discussions about further treatment until the doctor answered him on the "cure" question. The doctor, however, retained overall control during the interaction by refusing to answer the patient's question until he asked the "right" one. Ultimately, the medical dependency that the patient has on the medical professional directs the course of their communication.

Similarly, in situations where the patients try to exercise control by withdrawing, or ignoring the medical professional, medical dependency puts the medical professional in an advantaged position. If a patient refuses to communicate, they lose what little control they could have. Medical decisions will be made regardless of their input or feelings.

Patients who respond with "...I don't know how I feel..." or "...I don't care what you do..." usually do so
because they feel that responding won't make any difference. In these cases the patients generally allow their medical dependency to dictate their communicative strategy.

**Homeostatic Devices**

Patients and medical professionals alike developed several unique ways of dealing with many of the unpleasant aspects of terminal illness. Table 4.1 illustrates the devices, the situations in which they were used, and their purpose. A homeostatic device operates like negative feedback; it aids in "achieving and maintaining the stability of relationships" (p. 31). Chief among the homeostatic devices employed by both sides was humor. To illustrate, older female patients were teased by younger doctors about dating other men; older gentlemen were referred to as the most eligible males in the hospital. These are examples of the typical bantering and joking that went on during work rounds. These humorous exchanges among medical personnel and patients were frequent and appreciated; they were emotional holidays. Homeostatically, they allowed the patient and medical professional to communicate on a non-medical, non-disease related plane. In essence, both parties were able to abandon their roles as medical professional and patient and achieve and maintain a different, less threatening relationship.

Pain and fatigue were also used as safety mechanisms.
<table>
<thead>
<tr>
<th>DEVICE</th>
<th>SITUATION</th>
<th>PURPOSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Humor - mainly a device used by the medical professional</td>
<td>Patient Rounds: Patient in pain</td>
<td>Ease patient concern, reduce anxiety</td>
</tr>
<tr>
<td></td>
<td>Change in medication</td>
<td>Assurance that change is minor</td>
</tr>
<tr>
<td></td>
<td>Discontinuing treatment</td>
<td>Allows patient and doctor to ease into difficult-to-discuss facts concerning patient condition and disease progression.</td>
</tr>
<tr>
<td></td>
<td>Patient despondent or depressed</td>
<td>Brighten patients mood - lend support and caring.</td>
</tr>
<tr>
<td></td>
<td>Patient angry or belligerent</td>
<td>Calm fears - used as an invitation to discuss what is causing the upset.</td>
</tr>
<tr>
<td>Pain and/or Fatigue patient device</td>
<td>Patient faced with feared bad news from doctor or nurse</td>
<td>Avoid interaction - even though patient already knows what information will probably be.</td>
</tr>
<tr>
<td></td>
<td>Visiting hours or work rounds</td>
<td>Avoidance of contact with staff members and family - self imposed isolation.</td>
</tr>
<tr>
<td>DEVICE</td>
<td>SITUATION</td>
<td>PURPOSE</td>
</tr>
<tr>
<td>----------------------</td>
<td>-----------------------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>God - patient device</td>
<td>Usually - work rounds or family visits</td>
<td>To find a purpose for physical condition, or to place guilt and create despair.</td>
</tr>
<tr>
<td></td>
<td>(Patient usually directs question to medical professional. Why is God doing this? Why doesn't God take me?)</td>
<td>Place medical professionals in a position of helplessness. Reestablish everyone's helplessness.</td>
</tr>
<tr>
<td>Moaning - patient device</td>
<td>Patient in distress (mild) - work rounds family visits.</td>
<td>Proof of suffering/reason for discontinuance of contact or conversation.</td>
</tr>
<tr>
<td></td>
<td>Patient unhappy with treatment - annoyed at situation.</td>
<td>Expression of annoyance, unhappiness, anger.</td>
</tr>
</tbody>
</table>
Frequently, patients used fatigue or physical distress as reasons for ending a conversation which threatened a relationship. These incidents were the rare times when patients were "one-up" in the interaction, particularly if they were being deceptive. Unpopular family members were frequently greeted by a snoring patient.

In a number of interactions with certain patients, "God" was used as a homeostatic device. When the doctor began to explain to the patient that there was nothing more surgically or chemically they could do, the patient interrupted and asked everyone present why God would not take him or her; thereby absolving the doctor of blame, and preserving their relationship.

Generally it appeared that the homeostatic devices developed by the patients and medical professionals provided the flexibility they needed to deal with different situations. At the same time, these devices supplied the stability necessary to maintain the relationships.

**Education**

The difficulties encountered in working with the terminally gives rise to questions concerning how people are trained to deal with the dying. The education received in medical school focuses on how to save lives. When interns do a rotation on the PCU the limitations of their
training become apparent. They are not trained to allow people to die, therefore the PCU becomes a traumatic experience for new doctors. For example, during the first week of a rotation, a young intern stood outside a patient's room discussing her (patient's) condition with the resident and the medical director of the unit. He went on at length explaining the treatment options he thought were available for the patient, and that he intended to suggest these options to the patient. Both the medical director and the resident agreed with the suggested treatments, and then discussed with the intern all the reasons why these treatments would be useless. The young man was visibly shaken by this unexpected confrontation with these medical and personal limitations. After reconciling himself, the group—resident, director, intern, author—proceeded into the room, and the intern conducted the morning visit.

In previous visits with other patients, including this patient, this intern was open, receptive and warm. Today he was abrupt, self-conscious, and tense. He was unwilling to engage in conversation; he did not establish eye contact with the patient for any extended period of time; he remained at the side of the bed toward the foot, played with the patient's chart; and was frequently disfluent. Outside the room the intern remarked on his inability to communicate with the patient. The resident assured him that
it takes time to adjust to a service like the PCU. Expectations of both the doctors and the patients have to change. These changes take time.

Even among the more experienced doctors there was difficulty evinced in the acceptance of death. For instance, during a patient care conference a doctor from the oncology unit was discussing a patient who had been transferred to the PCU. The patient was now being treated by the director of the PCU. As her disease progressed she began developing other forms of cancer for which the oncologist was suggesting treatment. The treatment suggested would have had unpleasant side effects, and, considering the woman's age, present condition, and her history of treatment, the primary physician had chosen not to treat the newest disease. The oncologist was not willing to allow this woman to die of this disease; while the director of the PCU realized that treatment would not have significantly prolonged life, and would have reduced the quality of the time remaining. The most interesting aspect of this confrontation however, was not who won. It was the fact that the oncologist would not say that he refused to let her die, nor would the primary physician say he thought they should let her die. Luckily, the woman was mentally competent and thus made the decision for them--she opted for no further treatment.
The two men represent the two major mind sets that generally categorize physicians— the cognitive-technical and the emotional-experiential (Barton, 1977). The orientations clash quite frequently in cases concerning treatment of the terminally ill; the technical orientation championing cure, the experiential supporting care. Both student nurses and interns depart from school with a strong technical foundation. It is apparent that only with experience do they attain an emotional foundation. Some professionals, even with experience, never attain the emotional dimension.

Conclusion

This observational research attempted to shed some light on a communicative situation that is unique and special. There is no time when communicating is more important or more difficult than at the end of life. The isolation and fear surrounding death needs to be met with support and understanding. It is important to communicate during this time in order to reduce the accompanying fear and isolation. However, the nature of the situation creates its greatest barriers. The isolation, psychological distortion, and physiological distress that accompanies the end stages of cancer create problems in communication that are new. These new problems require new approaches.
The terminal person has a completely different reality than does a person who is not terminally ill; the challenge is to understand that reality. Among medical professionals there seems to be no lack of a response to this challenge. What is evident, though, in this researcher's opinion, is an overwhelming lack of circumspection—medical professionals were not always aware of how their actions affect their patients (Henry, 1973). They were not always capable of perceiving what they did in relation to how it affected others (Henry, 1973, p. 16). In many ways this condition could be spawned by a basic inability in any person to comprehend what it is like to die.
CHAPTER FIVE

DISCUSSION

Summary of Results

In Chapter 1 it was suggested that terminal illness creates a unique context for communication. Observations by experts and empirical studies indicated that feelings about mortality have important consequences for communication. This study attempted to determine these consequences. Based on previous research, we investigated the effects of medical professional's feelings about mortality on communication with the terminally ill. This investigation generated a number of sub-questions which were also addressed within the study. A general theoretical model was presented in Chapter 1 as an explanation of how attitudes about mortality might affect communication with a terminal patient. The model stated that attitudes of doctors and nurses about mortality could cause feelings of anxiety resulting in anxious behaviors (also called apprehensive behaviors) causing uncertainty in communication with the dying.

A questionnaire was administered to doctors and nurses asking them about how they perceive that they communicate with a terminally ill person. Some of the participants
worked strictly with terminal patients, the others had various patients. The questionnaire was developed to examine six basic variables that were identified in the literature: tenseness, comfort, effectiveness, difference, mortality, and directness. These variables were organized into a model based on, and an expansion of, the general theoretical model presented in Chapter 1. The original model was expanded to include the variables identified in the literature and tested in the questionnaire. This path model identifies and labels some of the components which were suggested by the original model, and also includes components that were not clearly represented in the first model. In the path model, feelings of anxiety composed the tenseness factor, and anxious or apprehensive behaviors were represented by the comfort, directness, and effectiveness factors.

Following these changes, a path analysis was performed to measure the relative effect of each independent variable on the dependent variables. The results indicated that attitudes about mortality moderately but significantly effect the tenseness felt in communication with the terminally ill. In actual communication this tenseness effects the comfort, directness, and effectiveness evinced in the medical professional/patient dyad. The results also indicated that attitudes about mortality slightly influenced
viewing the terminally ill as different from other patients, but that this has little effect on tenseness felt in communication.

To place these findings in perspective, t-tests were done comparing groups with different amounts of exposure to an experience with the terminally ill. It was felt that exposure and experience could influence attitudes toward the terminally ill and therefore influence communication. Results generally indicated that exposure to and experience working with terminal patients affected how well nurses perceived that they communicate with terminal patients. The more contact they had, the better they felt they communicated.

Among the palliative care unit (PCU) doctors there was a strong negative relationship between perceived ability to communicate and physical contact. Physical contact decreased as perceived ability to communicate increased. Two factors may play a role in this relationship. First, medical codes of ethics are particularly concerned with a doctor's professional conduct (American Medical Association, 1957). One of the ways professional conduct is measured and maintained is physical contact. Doctors are careful about physical contact with a patient and, therefore, do not use it as eye contact to communicate. Another reason for this negative relationship between physical contact and communication is related to the first. Within the medical setting it is dif-
difficult sometimes to separate medical from purely communicative contact. Doctors may not distinguish between the two types very easily, therefore, they may see more touching as medically warranted rather than communicatively induced.

Within the same group, a positive relationship was noted between eye contact and perceived ability to communicate; eye contact increased as perceived ability to communicate increased. This may be a direct result of a doctor's limited opportunity to communicate physically. Since eye contact would be considered an appropriate means of communicating, then it would increase as a doctor communicated more effectively.

Finally, all age groups were compared on feelings about mortality. It was felt that age might influence feelings about mortality. Results showed no differences among the age groups on feelings about mortality.

**Variables Affecting Communication with the Terminally Ill**

The variables identified in the literature and examined in the questionnaire seemed to be present in actual doctor-patient interactions as well. Many of the observations previously made by experts were replicated during the five weeks of observation on the palliative care unit (PCU).

For example, much of the literature stated that med-
medical professionals fear death, may choose to enter the medical profession because of this fear, and may feel helpless and angry when a patient dies (Davitz and Davitz, 1980; Feifel, 1977; White, 1977; Airing, 1968; Garfield, 1977). These attitudes were in evidence on the PCU. Based on personal observations, those medical professionals who were comfortable with their own mortality were few in number, but were always willing to discuss dying openly; those who were not comfortable with dying refused to discuss it, or were evasive. In conversation, if a question like "how do you feel about death?" or "how do you think you will die?" was asked, those medical professionals who seemed comfortable with the subject responded at length. They would discuss what they thought death might be like, where people go when they die, what it feels like to be dead, and ways of dying. Those who seemed uncomfortable usually answered with "...I try not to think about it...," or "...I don't like the idea, but I don't know how to get out of it..." Generally, if they were uncomfortable they answered in one of three ways: with a joke, with a statement ending the discussion, or no response—a shrug or "...I don't know..."

On the other hand, patient death is looked at quite differently than death in general. Patient death is viewed from two different perspectives by the medical professional. Barton (1977) labeled them the cognitive-technical approach
and the emotional-experiential approach. Depending on the relationship established with the patient, either one or both approaches may be operative. For example, if a nurse or doctor knew the patient for a period of time before the patient died, reactions to the death would be personal as well as technical. That is, a nurse or doctor may take the death as a personal loss, as well as one of the aspects of their job. However, if a patient was new on the unit and died, the reactions of the medical professional might be less personal and more technical. These observations imply that feelings about patients can change over time—relationships are established and friendships may even start. Clearly, time is an important variable affecting the perspective of the medical professional. Even more important, however, are the implications that these approaches have for communication.

Barton (1977) suggests that the feelings generated by the death situation force medical professionals to move in the direction of polarized positions—cognitive-technical or emotional-experiential. He further states that these approaches exhibit themselves as control and acceptance (understanding) respectively. Similarly, in their article on interpersonal communication, Steinberg and Miller (1975) suggest that the rules people use to govern their communication are determined by their fundamental orientations—controlling or understanding. Thus, it was not surprising
that a direct relationship was observed between orientation to the medical situation, and the rules governing communication in the situation. This relationship will be discussed in more detail later in this chapter.

Items covering tenseness on the questionnaire used physical contact and eye contact as their predictors. However, it should be noted that it is difficult to avoid physical contact in a medical setting, therefore, as an indicator of tenseness, it is not as reliable as eye contact. This is also true observationally. It was difficult to determine whether physical contact was medically warranted or communicatively motivated. It did seem, however, that the medical professionals who appeared comfortable with the patient had more overall physical contact with the patient. However, limited physical contact was almost always a sign of uneasiness. This observation does not seem to be supported by the empirical findings which negatively correlated communicative ability and physical contact. As was suggested previously, part of this inconsistency may be due to the fact that the distinction between medical and non-medical contact may not be perceived clearly by the medical professional.

To illustrate, among the nurses and doctors who were permanently assigned to the palliative care unit (PCU), patient contact (touching) was frequent and extended;
handholding might continue throughout an entire visit. The same observation was not true of some residents and new interns. During work rounds some residents and most staff members stood at the side of the bed, close to the patient's head, and held the patient's hand or rested a hand on the patient's shoulder. Others, however, stood at the foot or side of the bed toward the foot, touched the patient fitfully, if ever, and avoided eye contact by playing with stethoscopes, bed-railings, linens or personal articles of clothing--ties, belts, etc.. It seemed that if the medical professional were truly at ease with the patient, that medical and non-medical touching all communicated the same message; whereas, physical contact was limited or noticeably awkward when the medical professional was tense.

Comfort, effectiveness, and directness, variables #2, 3, and 6 respectively, were usually the hallmarks of those medical professionals who were at ease talking about their own death. Occasionally, a medical professional would be too direct with a patient. This was often a characteristic of new interns on the PCU. However, it quickly becomes evident in dealing with a terminal patient that being too direct or too evasive is equally inappropriate. New interns, generally were at one end of the scale or the other.
The last variable, difference - #4, focused on whether medical professionals feel terminal patients are different, and if this changes the way they communicate with them. Generally, it was observed that the terminally ill were viewed differently, but that this difference affected communication less and less over time. That is, with time the fact that a patient was terminal decreased in significance. However, it seemed that the closer the patient came to death, the more the medical professional would talk about dying with the researcher and other members of the staff. Comments like "...what a difficult way to die...," "I don't ever want to die that way...," and "...dying is so hard..." seemed to indicate that patient death caused some reflection on personal destiny.

Effects of Attitudes About Mortality

A path analysis performed on the model developed from the general theory presented in Chapter 1 supported the suggested effects of attitudes about mortality on communication. Attitudes about mortality not only affected the amount of tension felt in communication, but also how medical professionals view the terminally ill--as different from other patients because they are dying.

It was noted that new patients on the PCU appeared to be approached cautiously at first. There was little
joking—all communication seemed to be on a serious level. After instructions were given, and introductions were made, the conversation would be directed toward the family, if they were present. Frequently, the family and the medical professional(s) would talk as if the patient were not in the room. However, after a period of time, a week or more, interactions between the medical professional and the patient became more open and direct. This type of communication generally continued until the patient came very close to death, at which time interactions significantly decreased. In light of these observations it would appear that attitudes about mortality and how we view the terminally ill not only effect each other, but that both of these variables are also affected by patient condition and time.

Overall, it is apparent that attitudes about mortality influence how we view and communicate with the terminally ill. But, though we may view the terminally ill as different, this does not necessarily effect how we communicate with them. Our views of the terminally ill are apt to change due to the length of time spent with the patient, and the stage of their disease. Even though developing relationships with the terminally ill is hindered by the psychological and physiological effects of disease, it is still possible. And this development of relationships is affected by how we view the terminally ill.
Effects of Experience, Exposure and Age

It became obvious after a few weeks of observation that other factors besides attitudes about mortality and how we view the terminally ill were effecting communication. Two factors, length of relationship and stage of disease, have already been discussed. Since observation on the PCU allowed the researcher to watch both medical professionals with experience in the unit and newcomers--nurses and interns--some conclusions about experience and exposure can be drawn. To test the validity of these personal observations, t-tests were done comparing groups with limited exposure to terminal patients to PCU nurses, and groups with limited experience to PCU nurses. The empirical results confirmed the ethnographic observations. Palliative care unit (PCU) nurses perceived that they communicated well with terminal patients; whereas the nurses with less exposure and experience did not express the same confidence. Observations on the unit verified these perceptions. New staff members were less open, and more evasive with patients, while the more experienced staff members were more direct and generally calmer around the patients.

Also, it was thought that the age of the medical professional might have an effect on how they viewed mortality, and this would effect how they communicated with dying patients. This relationship was not supported by
empirical findings or observations. The age of the medical professional seemed unrelated to how they felt about death or how they communicated with a terminal patient. Apparently, how old you are does not influence your attitudes about mortality as much as one might think. Personal philosophies about life, religious beliefs, personal experiences with death may all be variables that impact more strongly on attitudes about mortality. And the development of these variables is not necessarily affected by age alone. However, the amount of exposure to and experience with a dying patient seemed to have an effect on the amount of confidence displayed in the medical professional/terminal patient interaction.

Probably the most directly observable display of confidence on the part of the medical professional was eye contact. In his research on communication apprehension, McCroskey (1977) indicates that there is a strong relationship between confidence and amount of eye contact during an interaction. This finding was clearly observable on the medical professional-patient dyad. The medical professionals who seemed at ease with their patients had noticeably more and extended eye contact with their patients than did medical professionals who seemed uneasy. This observation was partially verified by a Pearson product-moment correlation which yielded a positive relationship between perceived eye contact
and perceived ability to communicate among PCU doctors. The confidence which seemed to result from exposure and experience, however, did not display itself in the form of increased physical contact. This observation was also verified by a Pearson correlation—physical contact and ability to communicate were negatively correlated. As was stated previously, there could be two possible explanations for this. First, physical contact is carefully monitored in medicine; it is a sensitive area governed by professional and ethical codes. And second, since physical contact is an integral part of the performance of medical duties, it may be difficult for the medical professional to distinguish where medical contact ends and personal contact begins.

Review of Research Questions

In order to gain a perspective on these findings, let us investigate what answers this information supplies for the research questions. Each question will be discussed, beginning with sub-question #1: how do medical professionals view terminal patients? It was discovered that medical professionals do view terminal patients as different than other patients, but that this difference is apt to change as relationships develop and patient condition changes. As relationships developed, the fact that the patient was terminal seemed to exert less influence on the dyad. The focus
of messages became less medical and more personal. Discussions about events in the patient's future--the marriage of a son or daughter; the birth of a grandchild, and discussions about politics, weather, and books were frequent in a comfortable dyad. However, the relationship quite often would go through noticeable changes as the patient's condition worsened. The emphasis would again shift to the medical concerns and become less personal.

In some cases patients resisted the establishing of any kind of personal relationship. Some would only respond to medical inquiries, others were verbally abusive and, thus, discouraged personal contact. When a patient's condition worsened, they frequently had little strength with which to respond.

In most cases it seemed that if the medical professional and patient viewed the terminal patient as going through a "normal" process, the relationship seemed stable. However, in cases where the patient was viewed clinically--as a case to be worked on, then both the patient and the medical professional had difficulty maintaining a relationship. The patient seemed to resent the medical professional's limitations, and the medical professional resented the patient dying.

For sub-question #2: do medical professionals perceive that they change the way they communicate with a ter-
minal patient, evidence suggested that medical professionals were aware of differences when communicating with a terminal patient. On sub-question #3 results indicated that medical professionals do perceive more tension, anxiety, and apprehension in their dealings with dying patients.

Results also indicated, for sub-question #4, do medical professionals perceive that they have less physical contact or less eye contact with a dying patient, that eye contact may be affected by the fact that a patient is dying; but, because of the nature of the medical setting, a prediction about physical contact cannot be made. Sub-question #5, how do medical professionals view their own death, is the most difficult to answer. If the researcher's observations may be generalized, it could be stated that the medical professionals who worked consistently with the terminally ill tended to view death as a part of life. However, those medical professionals who had limited contact with the terminally ill tended to view their own death as an event which was separate and distinct from living.

Finally, on sub-question #6, does age, experience or exposure to terminal illness effect how medical professionals communicate with the terminally ill, findings indicated that experience and exposure did affect communication with the terminally ill, but that age did not.
It should be noted that the differences that appeared among the groups represented in this study seemed to be due to the fact that some of the participants worked strictly with terminal patients while the others did not. Repeated exposure to terminal illness does allow an individual to adjust to the sights, sounds, and feelings which accompany the process of dying. Therefore, it must be noted that these findings are based on comparisons of people who are familiar with death with people who are unfamiliar with death. Thus the answers to the sub-questions must be evaluated in this light.

The answers to these sub-questions now allow us to answer our major research question: How do medical professionals' attitudes about mortality affect communication with the terminally ill? Clearly, both the empirical and observational findings indicate that attitudes about mortality may cause increased feelings of tenseness which in turn affects the comfort, effectiveness and directness in a medical professional/patient dyad. A number of observations led to this conclusion. First, those medical professionals who in conversations had expressed comfort with their own mortality, were generally those people who seemed most comfortable with terminal patients. Second, those medical professionals who were willing to talk openly about their own mortality, were also those who seemed most direct and
open with patients about their condition, dying etc. Third, those medical professionals who seemed comfortable with dying, generally succeeded in effectively communicating with patients about the patient's concerns about dying. Finally, tenseness, evasive answers, inability to discuss dying related issues with the patient or the researcher, generally were the hallmarks of those medical professionals who were reluctant to fill out questionnaires or talk about personal mortality.

Implications for Medical Professional-Patient Communication

Communicatively, terminal illness presents a unique context. It is a context of uncertainty on the part of both the medical professional and the patient. It is a context of fear, as well. To establish a relationship within this context is not only difficult—-it is crucial. Medical professionals need to be aware of the fact that dying can be a process of being isolated from life. That, in fact, patients die communicatively, long before they die physically. Thus, it is imperative that medical professionals realize the importance of establishing and maintaining relationships with terminal patients for as long as possible.

Since it has already been established that the medical professional/patient relationship is characterized by patient dependence, medical professionals must be made
aware of their ability to influence patient behavior. If, as this research suggests, their attitudes about mortality influence the way they communicate with the terminally ill, they should take steps to examine these feelings. Discomfort caused by unresolved feelings about mortality will not only affect the way the medical professional communicates, but will impact on the patient as well. As was suggested by Watzlawick et al. (1967) our communication not only conveys information, but determines behavior, as well. A medical professional who is tense when communicating with a terminal patient, may generate feelings of insecurity, or fear on the part of the patient. If communicating well with a terminal patient is our goal, then one cannot ignore the importance of one's attitudes about mortality, and how it impacts on communication in this situation.

The importance of communicating effectively with the terminally ill is tantamount to medical effectiveness. The context of terminal illness makes effective communication crucial. Misunderstandings can lead to false hopes or tragic disappointments. This fragile context is further compounded by the fact that we are not always aware of what is important to a terminal patient. A missed phone call or a missed visit can have a devastating effect on a terminal patient. The balance between their psychological
state and physiological state is delicate; a change in the former can have serious consequences for the latter (Feifel; 1977).

Effective communication may be hampered not only by the medical professional's attitudes, but by the patient's attitudes, as well. For example, if a patient is convinced that there is something that can be done, they can be outraged by a medical professional who tells them something different. A patient who does not fully understand or accept his condition presents barriers to effective communication that only time can break down. The most effective communicators were those who were patient, and allowed the terminal patient to adjust to their condition without masking the truth. The effective communicators attempted to accurately understand the patient and help the patient to understand the medical professional. Also the medical professional worked with the patient to establish and reach common goals.

Besides needing to be talked to honestly and openly, patients frequently need to establish contact with people. Often when a patient is told that they are terminal, it disrupts long-standing relationships. If the disease presents itself physically, the patient may refuse to see friends. If the patient is angry about the situation he may respond by attacking and alienating those people who care.
about him/her. The implication here for the medical professional and the patient seems clear. As Watzlawick et al. states, "...quite apart from the mere exchange of information, man has to communicate with others for the sake of his own awareness of self..." (1967, p.84) If the patient has isolated himself from his family and friends, the medical professional may be his only source of confirmation. The medical professional has the power in this situation to influence the behavior of the patient--not by telling him or her what to do, but by encouraging the patient to communicate. Medical professionals need to direct patient attention to growth through the experience of dying.

Limitations

Attitudes about mortality represent only a small segment of the variables affecting communication with the terminally ill. In fact, only the effects of a small determinant of attitudes were represented in this study. Type of disease, length of illness, communicative ability of patient, setting, etc., affect communication with the terminally ill.

Besides the limited scope of the independent variables, the subject itself imposes limitations. Studying the medical profession is difficult because of the protection and privacy it must guarantee patients. In addition, study-
ing any patient/medical professional interaction is delicate
due to considerations of confidentiality and invasion of
privacy. When a patient is dying, considerations of dignity,
decorum, and humanity also come into play. Many of these
considerations limited what questions could be asked, in
fact, direct questions addressed to patients were prohibited.
Answers to questions concerning a patient's attitudes about
mortality and how they perceived people talked to them would
have enriched this study, but were not permissible. The
only hope of ever obtaining information like this would be
through patient self-reports.

Pencil and paper data collection was hampered by busy
schedules and unwillingness to cooperate, despite the fact
that the questionnaire had been made as brief as possible.
Similarly, observational data was limited, as some people
refused to be observed. Thus, because those who allowed
observation were at least tolerant of this research, some
observational bias exists.

In addition to subject bias, the observational
research was also limited by personal bias. It was difficult
to separate what did happen from what the researcher thought
would happen. Also, the researcher had had a personal ex-
perience with death prior to performing the observational
research on the palliative care unit. The researcher's
father died on the unit in March.
The questionnaire design, although it was easy to fill out and was quick, did not yield enough information for clarification of the ethnographic observations. It must be recognized, however, that, while a more detailed questionnaire might yield more information, it would also yield a smaller sample. Also, the adjective choices were not consistent throughout the questionnaire; some were truly bipolar and a few, such as 15, 16, and 17, were not (See Appendix A).

Overall, the best information was gained through ethnographic observation. Although it is the most difficult for which to gain permission, it is imperative in this type of research. In fact, after doing both, the questionnaire or any attempt at a pencil and paper measurement would be abandoned by this researcher in the future. However, one must also be aware of the limitations of observational research inherent in the researcher. This type of research requires not only perceptivity, sensitivity and practice, but familiarity with subject, setting, institution etc. A researcher must first be familiar with what is the norm, before he/she can detect change.

**Implications for Future Research**

Both the patient and the patient's family need to be studied in order to understand the total communication system.
For example, further studies could examine the effect of the family's attitudes about mortality on communication, and the effects of the patient's attitude about mortality on how he/she communicates. Although studies in either one of these areas would have ethical and institutional problems, they warrant consideration.

Findings in this study also suggest a closer investigation of the effects of experience and exposure. A longitudinal study could be conducted over a period of years on new interns and nurses. One group of doctors and nurses working strictly with terminal patients and the other group working with various patients could be compared.

Another area that could be investigated is the effect on family communication with the patient dying at home instead of in the hospital, or just the affect terminal illness has on family communication in general. Either study could yield valuable information on the changes that terminal illness causes in communication patterns.

An in-depth study of how medical professionals are trained to deal with death, deliver information about it, and cope with it personally, could construct the groundwork for improving medical professional communication skills. But probably the most needed study of all is a study of research methods that are appropriate for the medical setting--
a comprehensive evaluation of methods that are practical and efficient.

It became clear in this study that one of the best ways to study communication with the terminally ill is through observation. Pencil and paper instruments are simply not appropriate in this setting. They require time which medical professionals don't have, they may threaten the individual, and they are not sensitive enough to capture the nuances within the patient/medical professional dyad. This raises a final limitation within this study and an implication for future research--how to train observers and standardize observations in a medical setting.

Concluding Remarks

Based on empirical findings and observation; this study does offer some insight into how attitudes about mortality may affect communication. It is, however, a very small step. Knowing that a fear of death may cause us to be tense while talking to a dying person does not offer much of a practical solution to problems. What we must realize from this study is that we need to joust with our own feelings about mortality before we can attempt to understand and relate to someone who is dying.

Also, the medical professional needs to develop a relationship with a patient that is honest and open--being
honest with a patient even when they deny the truth. This does not mean being tactless, but it does mean telling the patient what he or she should know.

Patients also need to realize that the position of the medical professional may be as precarious as their own. It is not easy to tell someone they will die, or to realize that there is nothing that you can do to save them. Patients must also be aware of how they feel about death in order to measure its impact on their behavior.

Both the patient and the medical professional need confirmation in this situation; the patient because he/she is dying, and the medical professional because he/she is helpless to prevent it. The parties need to work together, not ignore each other. The need for understanding is great on both sides.

The goal of this study is not to help only those patients who have been labeled terminal. It was conducted for every person, because we will all die one day. The special significance here is that if we do not come to grips with our own mortality, then we will be sentenced to the same isolation that terminal patients suffer now. And we will be isolated from life long before we physically die.
LIST OF REFERENCES


McCroskey, J.C., Richmond, V.P., Daly, J.A. & Cox, B.G. The Effects of Communication Apprehension on Interpersonal Attraction. Human Communication Research. 1975, 2, 1.


APPENDIX A

Department of Communication
University of Delaware

This questionnaire is intended to survey communication practices and attitudes. It is part of a larger study focused on communication with the terminally ill. The questions cover some of the ways in which medical personnel interact with the terminally ill. Ultimately, the information will be used in a master's thesis.

You are under no obligation to answer all questions. Data will be kept in the communication department for one year and destroyed at the end of this study. Data will be available by coded number only.

Since this area of study is beneficial to all people, we would appreciate your responses. Thank you for your cooperation.

Demographic Information:

Sex: ___ Male ___ Female

Age: ___ Under 20 ___ 21-25 ___ 26-30
      ___ 31-35 ___ 36-40 ___ over 40

Educational Background

___ college ___ nursing school ___ medical school
___ Other (please explain)

Consent Form

I, __________________________, have read the description of this study and agree to participate. I understand that all results will be confidential.

Signature __________________________ Date __________________________

Note: the above consent form will be removed before the questionnaire is reviewed.
1. Do you consider terminal patients different from other patients?
seldom — — — — — — — — usually

2. Are you comfortable talking about death with a terminal patient?
uncomfortable — — — — — — — — comfortable

3. How often do you just "visit" with a terminal patient (on your own ward, not a family member)?
rarely — — — — — — — — often

4. How well do you feel you communicate?
poor — — — — — — — — very well

5. Do you think that your ability to communicate effectively is apt to change when you talk to a dying person?
seldom — — — — — — — — usually

6. Generally, do you feel you communicate effectively with a terminally ill person?
ineffective — — — — — — — — effective

7. Are you ever tense when talking with a dying person?
always — — — — — — — — never

8. Does the fact that a person is dying make you anxious?
seldom — — — — — — — — usually

9. Are you apt to take the death of a patient as a personal defeat?
seldom — — — — — — — — usually

10. Do you ever feel apprehensive when communicating with a dying person because they are dying?
ever — — — — — — — — occasionally
11. Are you ever unable to express yourself accurately when communicating with a dying person?

never_______ ______ ______ ______ ______ ______ occassionally

12. Do you ever avoid physical contact (non-medical) with a dying person?

never_______ ______ ______ ______ ______ ______ occassionally

13. Have you ever found yourself avoiding eye contact with a dying person?

never_______ ______ ______ ______ ______ ______ occassionally

14. Are you apt to have the same amount of eye contact with a dying patient as you would with a "regular" patient?

seldom_______ ______ ______ ______ ______ ______ always

15. Do you avoid making direct statements to a dying patient about his/her condition?

seldom_______ ______ ______ ______ ______ ______ always

16. Are you apt to think about your own mortality when you deal with a terminally ill person?

seldom_______ ______ ______ ______ ______ ______ always

17. Does the fact that a patient is terminal change how you communicate with them?

seldom_______ ______ ______ ______ ______ ______ usually

18. Are you comfortable talking about your own death?

uncomfortable_______ ______ ______ ______ ______ ______ comfortable