

INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

UMI

**A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor MI 48106-1346 USA
313/761-4700 800/521-0600**



NOTE TO USERS

The original manuscript received by UMI contains pages with indistinct and/or slanted print. Pages were microfilmed as received.

This reproduction is the best copy available

UMI



UNIVERSITY OF OKLAHOMA
GRADUATE COLLEGE

SPEAKING ABOUT DEATH: AN ETHNOGRAPHY OF
SPEAKING, A STUDY OF A COMMUNITY HOSPICE

A DISSERTATION

SUBMITTED TO THE GRADUATE FACULTY

in partial fulfillment of the requirements for the
degree of
Doctor of Philosophy

By

Karl V. Winton
Norman, Oklahoma
1998

UMI Number: 9828787

**Copyright 1998 by
Winton, Karl V.**

All rights reserved.

**UMI Microform 9828787
Copyright 1998, by UMI Company. All rights reserved.**

**This microform edition is protected against unauthorized
copying under Title 17, United States Code.**

UMI
300 North Zeeb Road
Ann Arbor, MI 48103

c Copyright by Karl V. Winton 1998

All Rights Reserved

SPEAKING ABOUT DEATH: AN ETHNOGRAPHY OF SPEAKING, A
STUDY OF A COMMUNITY HOSPICE

A Dissertation APPROVED FOR THE
DEPARTMENT OF COMMUNICATION

BY

Dawnie Wicks

monica harris

Ph. D.

Ph. D.

Dan O'Hair

ACKNOWLEDGMENTS

"What a strange, strange, trip this has been." These song lyrics written and sung by the Grateful Dead, have been the watch-phase of my graduate education. I began this journey in Communication Studies in 1986. Here it is 1998 and indeed this has been a long strange trip. This journey began for me in 1984 in the field of Anthropology and has ended twelve years later in the field of Communication. Many unforeseen stops and hazards have occurred along the way. A change of academic fields, a Navy Reserve career, the Gulf War, a motorcycle accident, and the raising of a family resulted in lengthening my stay as a graduate student..

To tell the truth, I never thought that I would ever get to the finish line, but here I am, in spite of myself life's turns, and I know that I have not gotten here by myself. I have had a great deal of help from many people on this journey, and I owe them a great debt. I thank, you, the many unnamed contributors who have helped me throughout the years along this long and very strange

trip called graduate school.

First and for most, I wish to thank my wife Betsy, who has put-up with me and my obsession to earn this doctorate degree. She has suffered greatly because of this obsession of mine, and I appreciate it very much. I owe her far more than I can ever repay. Second, I want to thank my step-daughter Victoria Rene' Morgan who probably thought that this day would never, come. It has, so where is the briefcase?

I also wish to thank my mother Mrs. Margie Winton who has given her financial and emotional support to me throughout the years as well as her encouragement. My sister Nancy Lee Winton has always been there for me behind the scenes giving advice and an understanding ear.

My good friend, Mrs. Pat Dugan has given her insightful critique on this manuscript (whether I wanted it or not) as well as her continual encouragement throughout my days as a graduate student. Mrs. Dugan provided me with insight and understanding into the world of bedside nursing and medical terminology. I thank you for this from the bottom of my heart, and you did in fact, live to see this day!

In addition, I want to also thank my friends Phyllis Frazier and Sherylann Densow who were my sounding boards from the beginning to the end of this writing process. I sincerely appreciate your contributions, your encouragement, and the many very long telephone conversations.

This dissertation would not be possible without the help of all the staff members of the hospice where I did my research. Although they were not sure why I was there and what I wanted to observe, they helped me, accepted me and my many endless questions, and treated me as one of their own.

In addition; An ethnographic study of this kind owes a great debt to the people being studied. Given the anonymity of my informants, I cannot mention them by name. However, I do want to thank you and the many individuals who gave their time to help gather this data and helped me to understand the mysteries of medical language and the workings of NC Hospice. I regret that I am unable to name each person and give proper official mention. However, I can say, Thank you one and all from the bottom of my heart.

I want to also thank my professors who have led me

in the quest of knowledge. Dr. Larry Wieder, Chair of my doctorate committee, has provided counsel, and invaluable help throughout the course of this study. He was one of the first faculty members I talked to when deciding to enter the Communication field and has been with me since this time giving scholarly support throughout this journey. It was through Dr. Wieder that I discovered phenomenology, ethnomethodology and the writings of Dell Hymes. He encouraged me to research the community hospice and to go in the theoretical direction that I did. His careful evaluation of this manuscript and his insightful comments have been extremely helpful in completing this document.

I would like to also thank Dr. Nussbaum for showing me how Communication studies and Health issues can merge together. Finally, I want to thank and acknowledge the other members of my dissertation committee Dr. O'Hair, Dr. Lujan, and Dr. Foster, for their insight and their contribution to my graduate education.

TABLE OF CONTENTS

CHAPTERS	PAGE
1. SPEAKING ABOUT DEATH: AN ETHNOGRAPHY OF SPEAKING, A STUDY OF A COMMUNITY HOSPICE	1
Introduction to how people talk about death	1
Purpose of the study	4
Scope of the Study	6
Death in Contemporary society	10
Hospice care of the dying	13
What is a Hospice	19
Definition of Terms	25
Research Questions	26
Organization of the Dissertation	26
2. REVIEW OF RELATED LITERATURE	29
Health Communication Research	30
Health Communication Literature	31
Related Thanatology Literature	41
Literature on Hospice	55
Ethnographic Literature	57
Summary of the Review of Literature	58

3.	METHODOLOGY	60
	Ethnography	62
	Ethnography of Communication	63
	Introduction to the Setting and the Subjects	66
	Participant-Observation and Interaction	67
	Summary	71
4.	THE SOCIAL SETTING: AN ETHNOGRAPHIC ENQUIRY INTO A COMMUNITY	73
	The Setting and Subjects	76
	Demographics	78
	Hospice organization and patient care	82
	Specific settings	84
	The roles of hospice staff	88
	Non-medical staff	89
	Hospice field Nurses Medical staff	94
5.	AN ETHNOGRAPHY OF COMMUNICATION: TWO SPEECH EVENTS	102
	The IDT Meeting: A Speech Event for talking about death and dying	109
	Background on Interdisciplinary Team Meeting	111
	The gathering together	114
	Opening Prayer	117
	Bereavement	120

The patient's medical assessment: The IDT	116
Announcements and the ending of the IDT	133
Staff Meeting	134
Discussion of the IDT	139
The Second Speech Event: The Patient's	
Bedside Environment	142
The Nursing Home	145
The Private Residence.	152
Teaching the family how to speak about	
dying and how to view it.	160
Conclusion.	163
6. SUMMARY AND CONCLUSION OF THE RESEARCH	166
Conclusion	168
Implications of Two Speech Events	169
Additional Observations	172
Recommendations for Future Research	177
ENDNOTES	180
BIBLIOGRAPHY.	181
APPENDIX A	198
APPENDIX B	200
APPENDIX C	212
APPENDIX D	213

APPENDIX E	216
APPENDIX F	217
APPENDIX G	221
APPENDIX H	222

List of Illustrations

Figure.....	Page
1. Floor Plan of NC Hospice.....	37
2. Hospice Organizational Chart.....	49

ABSTRACT

This study of communication and health care focuses on how hospice medical personnel and their terminally ill patients talk about death and dying. It is a qualitative ethnographic study of a community hospice. The issues the study addresses are how hospice nurses and their patients experience death, talk about death, and how they make sense out of the dying process.

The seven month study was conducted at an out-patient community hospice, located in a small city in central Oklahoma. Extensive participant-observation was conducted during regular patient visitation by the nurses, at the weekly IDT meeting and with the rest of the hospice staff. Using Dell Hymes perspective of, 'ethnography of speaking' this study provides insight into a specific communication settings by understanding, the structure and function of it.

**SPEAKING ABOUT DEATH: AN ETHNOGRAPHY
OF SPEAKING, A STUDY OF A COMMUNITY HOSPICE.**

CHAPTER 1

INTRODUCTION TO HOW PEOPLE TALK ABOUT DEATH

The goal of this research study is to develop an ethnography of speaking (discussed in chapters 3-6) by analyzing two different speech events: A weekly Interdisciplinary Team (IDT) meeting, and nurse patient verbal communication gathered from research conducted at a local community hospice. This meeting is a major weekly communicative event involving the open exchange of medical and social information between members of the health care team. Information exchanged during the course of the IDT determines the type of health or patient care hospice patients will receive until the next meeting.

Generally the study of health care communication centers on issues such as doctor-patient relations, compliance gaining, giving bad news to patients, and communication with other health care professionals (Kreps & Thornton, 1992; Sullivan & Reardon, 1986; Fitzpatrick,

Edgar & Freimuth 1992; Evans & Clarke, 1983; Korsch, 1989; Arntson, 1989; Nussbaum, 1989). However, study of communication and health care is somewhat different in scope than most communication research. It is a study that deals with an important health care issue which is not one normally dealt with in traditional health communication research.

The focus of this communication research is on how hospice medical personnel, the terminally ill, their primary care givers, their hospice health care nurses and their family members talk about death and dying. An ethnographic theoretical framework is used to study communication among these individuals and groups. This research studies how hospice and their patients talk about death, how they experience death and how they make sense out of their very personal experience of dying.

Death is not an easy subject for people of 20th century American culture to discuss openly in normal everyday conversation (Kreps & Thornton, 1992). As reported in death and dying literature, even when the topic of death is discussed, people talk about it in subdued voices and use various euphemisms to avoid saying the words: dead, death and dying (Kasterbaum, 1979, 1981;

Kalish, 1979; De Spelder & Strickland, 1983; Stephenson, 1985). The most common response to talking about death is that most people prefer to avoid the subject altogether, or when it is discussed, tell the individual that he/she is being morbid and quickly change the subject (Kreps & Thornton, 1992; Kreps, 1993) .

The ironic coincidence about death is that avoidance in conversation does not mean an avoidance of it in life. Death is there, always stalking us from the moment of our birth throughout our lives until it finally catches up with and takes us. Even modern science and medicine can not stop death; all they can do is delay the inevitable.

Since death is such a part of our lives, we should be able to talk about it freely and honestly in almost any social setting. However, this is not the case in the American culture, and this avoidance is true of both medical professionals (doctors and medical staff) and laymen alike. Doctors certainly do not like to tell their patients that they are dying, and patients certainly do not like to hear it, and they do not like to admit to it if they are (Glasser & Strauss, 1965; Evans & Clarke, 1983; Wortman & Dunkel-Schetter, 1979;

Stephenson, 1985; Nimocks, Webb & Connell 1987; Lukeman, 1982; Smith 1985; Thompson, 1989).

This then is the dilemma of dealing with death in contemporary American culture. If laymen will not or cannot talk about death, and doctors are reluctant to discuss the subject of death with their patients, then how do people who are dying or those who have to deal with the dying on a daily basis, talk about death and make sense of this very personal and individual experience?

Purpose of the Study

This study focuses on communication within a community hospice and how it is manifested by various members of the hospice staff, terminally ill patients, their families, friends, as well as their health care providers (Miller & Knapp, 1986). The setting of this study is a local community hospice for the terminally ill. My applied interest in this subject comes from an experience I had when a family member was diagnosed and subsequently died from terminal liver and pancreatic cancer.

In addition, I spent a year and a half as a hospice volunteer, aiding a man in a nursing home who was dying of prostate cancer and a congestive heart. These experiences have brought me into contact with doctors, nurses, various medical professionals and laymen in the environment of hospitals, nursing homes and home care settings in which they work. I have watched and listened to these people talk about the dying process with an intense personal involvement and with an acute academic interest. As a result, I have become fascinated with the verbal and non-verbal communication of patient and medical personnel within the context of the patient's impending death.

This applied experience of being involved in people's lives and their subsequent deaths has developed into a theoretical interest which lies in the dichotomy that exists between what a person says to others about what they believe and do, and what they really say and do in practice. I believe that this dichotomy can be best addressed by looking at the everyday concerns of the individuals who are involved. I further believe that we cannot continue to ignore communication surrounding death just because it is an uncomfortable subject to discuss

To do so would illustrate a serious void in the communication literature. Months of research and study has shown me that talking about death and dying is a topic that is both worthy and necessary in the health/medical communication field.

Scope of the Study

Americans enjoy talking about what is happening to themselves as individuals as well as to what is happening to others. This talk includes both good news as well as the bad news. In addition, patients diagnosed with a terminal illness also have this desire to talk. However, due to societal norms, cultural stigma or their emotional state, patients often are not allowed or are unable to discuss their own death and the process of dying with others. This impasse includes their family, friends and even their doctors and nurses (Hines, Moss & McKenzie, 1995; Hines, Babrow, Badzek & Moss, 1996; Ling, 1989; Hansen & Frantz, 1984; Cherry & Smith, 1993; Gotcher & Edwards, 1990; Thompson, 1989).

This hesitancy of patients to talk about their impending death is reflected in both health communication literature and literature on death and dying (Burleson,

1984, 1990; Gantz & Greenberg, 1990; Fitzpatrick, Edgar & Freimuth, 1992). Recently, studies in communication have focused on various HIV/AIDS related topics (Cline, Johnson, Freeman, 1992; Edgar, Freimuth, Hammond, McDonald & Fink, 1992; Perloff & Ray, 1991; Green, Parrott & Serovich, 1993; Reardon, 1990; Zook, 1993). Research studies in these areas have provided insight into a patient's hesitancy to talk about his or her impending death as well as the reluctance of most health care professionals to talk openly and honestly about death and dying to their terminally ill diagnosed patients (Harwood, 1995; Gotcher, 1993; Kreps, 1988; Lefeure, 1992; Sullivan, & Reardon, 1986).

The aim of this research is to address the topic of speaking about death in American culture, by examining some specific settings in which talking openly about death is commonplace. While there are many more settings in which death is discussed openly, I chose two settings that contrasted strongly with each other: a group setting and an individual setting.

Employees of hospice talk about death in many places such as: the patient's home, nursing home, professional settings and scheduled meetings. They also

talk about death using a variety of ways ranging from the use of professional medical terminology, to that of the colloquial terminology of the layman. Equally important is the description of how the field nurses deal with and understand death and terminal illness in light of the NC Hospice philosophy (see appendix A). What the nurses do or say about dying and death relates directly to how they interact with their patients, the type of care and even the style of health care given.

NC Hospice is an especially appropriate locale for doing ethnographic research into speaking situations about terminally ill patients because of the variety and visibility of death relevant speaking situations that emerge from the hospice team concept (Zimmermann, 1994; Zimmermann & Applegate, 1992). Each staff member employed at hospice has a specific role that distinctively shapes his or her interactions with the patient, with the primary care giver and with the patient's family.

For example in NC hospice, there is a distinction made between medical and non-medical staff roles. Some non-medical staff provide spiritual guidance, social and psychological help and counseling. While other non-

medical staff provide friendship, companionship, and relief for the primary care giver as well as, administrative, organizational and managerial support for the patient, the family and the field nurses.

This dissertation is an ethnography, specifically an ethnography of communication (see chapter 5), which describes various communication aspects of a community hospice located in a medium size city in central Oklahoma. The research studies death relevant speaking situations between hospice staff and patients with a diagnosed terminal illness who have six months or less to live. The study will look at how these individuals talk or do not talk about death with their family, friends and various health care professionals.

To better understand how communication by medical and lay people alike is used in dealing with terminal illnesses we need first to understand the perspective of death in American society since the mid-1950's. In addition, the term hospice will be defined philosophically and medically and the role it plays in dealing with terminally ill individuals will be examined.

Death in Contemporary society

Death is a subject that has intrigued mankind throughout history. We have told stories, thus creating mythologies and tales describing death and what happens when death occurs. In his book, The Denial of Death (1973), Earnest Becker says, "the idea of death, the fear of it haunts the human animal like nothing else; it is the mainspring of human activity-activity designed largely to avoid the fatality of death" (p. ix). He states that the fear of death is the primal motivation for human actions.

If we look at death from Becker's point of view, we can understand the basis for many of our religious and scientific beliefs. Death, for many of us, is a difficult and uncomfortable subject to discuss. However when death occurs, we want to know the details. Although we may not be willing to admit it to others, death holds a certain interest for us. When told about someone's death and after expressing condolences isn't the usual question asked, "How did he or she die?" We are drawn to the subject of death by curiosity, sincere interest, or as a way to better understand the death of a loved one.

Regardless of our reasons we are drawn to death like moths to a flame (Nuland, 1993).

It is a paradox that we are drawn to death for whatever reasons, however, we really do not want to face death, especially our own. Kreps (1988) says that this reluctance to speak about death illustrates our cultural stigma surrounding death and the dying process. This reluctance to discuss death hinders our ability to make sense out of death and the dying process. Instead of talking openly about death we disguise conversation about death in the traditional methods of folk tales, allegories, dreams and even jokes (Nuland, 1994).

Because of the medical revolution of the past 40 years, we have created a modern method of dealing with death. In the American hospital, a legitimized cultural institution, dying occurs, sanitized and isolated from the rest of society. In this setting death can be ignored and or dealt with by others. It is as if we have blinders on concerning the existence of death. In American culture, if we cannot see death occur, we do not experience the process of dying, therefore, death must not exist.

Just as we like to ignore and deny death, we create myths about it. One myth concerning death is that of the, "good death" or, ars moriendi, (Nuland, 1985, p. xvi). This myth is represented in literature, art, television and movies. An example of this "good death" is enacted by Hollywood every time some one dies in a movie. How can we forget the deathbed scene where grandmother is dying, and her husband, children, grandchildren and friends are gathered around her bed waiting for her last words and her peaceful departure from this world. This example of death is very far from what actually occurs at the time of death.

However, this is the type of death which we hope for or imagine for ourselves, and for our family and friends. But just what is this, "good death?" Nuland found that ars moriendi, was a "religious and spiritual endeavor, described by the fifteenth-century printer William Caxton as, 'the craft for to deye for the helthe of mannes sowle'" (p. xvi). Over time, this philosophy evolved into the culturally desirable idealized death, truly the right way to die.

This notion of a, "beautiful death," is made difficult in our society by the current method we use to

deal with death. Most deaths in America today occur not in the home with friends and family around but rather in the hospital or the nursing home, isolated from everyday life and human experience. In this way, we isolate and prevent the death bed scene we so desire and associate with the, "good death" scenario. By removing and isolating death from our everyday life experience, we also remove and isolate the communication interaction that goes along with it.

Hospice Care of the Dying

Hospice is a program of care designed specifically for the terminally ill and their families. It is an alternative to the normative way of dying, which is usually alone, and usually in a hospital setting. The official hospice belief system or ideology of death is closest to the model of a "good death" that we can have and is an aspect of the hospice code as discussed in chapter 6. Hospice not only provides physical care for the terminally ill patient, but gives attention to their emotional, psycho-social, and spiritual needs while also assisting the needs of their families (Smith, 1985).

The hospice ideology centers around support such as helping patient lessen or be free of physical and psychological pain, to help them make the most of the time that they have left, and to make their dying more comfortable, less frightening, and in every way more bearable (Beresford, 1993).

Hospice, as defined by the National Hospice Organization in one of their information brochures, is: a compassionate method of caring for terminally ill people. Hospice is a medically directed, interdisciplinary team-managed program of services that focuses on the patient/family as the unit of care. Hospice care is palliative rather than curative, with an emphasis on pain and symptom control, so that a person may live the last days of life fully, with dignity and comfort, at home or in a home-like setting. (National Hospice Organization, 1996)

In the hospice view (Stoddard, 1991), this is an alternative to conventional, cure-orientated medical treatment aimed at combating disease with any means possible, for as long as possible. Instead of pursuing aggressive treatments for terminally diagnosed

conditions, the focus of hospice is on patient palliative care, which is comfort and emotional support.

Doctors are taught to treat disease with a focus on recovery and cure (Stoddard, 1991). They aggressively manage diseases with progressive procedures, medicines and advanced technology. Sometimes the treatments exceed the physical and mental limits of the patients they treat. These doctors may continue with treatment and may even prescribe experimental, painful and costly treatments, even though the results may not have any more benefit in curing the disease or keeping the patient alive longer.

From the point of view of hospice (Stoddard, 1991), aggressive and continual treatment of disease needs to be contrasted with the actual desires and needs of the patients themselves. Palliative care is what hospice provides to the patients once the affliction can no longer be treated, and his or her condition is diagnosed by a physician as terminal with a life expectancy of 6 months or less to live. Thus the focus of palliative care is the relief of symptomatic pain associated with certain terminal illness (Smith, 1985). As the

appropriate treatment for the disease continues, the curative effort discontinues.

Hospice doctrine holds that the hospice staff should try, as much as possible, to return control of the patient's life to the patient. Hospice does this by allowing patients and their families to decide on schedules, treatments, meal plans, visitation, and medication. Hospice and its medical professionals provide guidance and also act as an advocate for the patient to help him or her sort out viable options and priorities.

The overall philosophy of hospice emphasizes the importance of quality of life for the dying. A pamphlet written by the National Hospice Organization describes the purpose and philosophy of hospice:

to provide support and care for people in the final phase of a terminal disease so that they can live as fully and comfortably as possible. Hospice affirms life and regards dying as a normal process. Hospice believes that through personalized services and caring community, patients and families can attain the necessary preparation for a death that is satisfactory to them. (The Basics, 1985)

Bresford (1993) and Smith (1985) state that the goal of hospice is to manage the patient's care as well as possible until death occurs. For most patients and physicians, the first step in managing care is to manage the patient's often chronic and severe pain.

After pain is relieved and or controlled, the hospice staff can give attention to social and domestic issues such as family problems related to the fear and anxiety of an impending death in the family. Then, there are various practical concerns such as: dealing with personal and family estrangements, problems with insurance, various government agencies, creditors, and the making of wills and planning of funeral arrangements.

When an individual is initially diagnosed as having a terminal illness, both he or she and his or her family often go through a difficult emotional time of adjustment and of acceptance of the illness. Hospice helps in addressing some of these issues of adjustment and acceptance by providing a safe open non-judgmental environment. In the hospice view (Stoddard, 1991), if these problems are not brought out in the open and discussed, the results for the patient and the patient's

family could be increased confusion, isolation, depression and grief.

Hospice literature (Anderson, 1992; Smith, 1985; Stoddard, 1991) notes that it is commonplace for patients diagnosed with a terminal disease such cancer to often avoid calling the disease by its name. This is a strong indication that they are in denial of their medical condition and present diagnosis. Often the family of a terminally ill patient will do the same by refraining from using the words "cancer", "terminal" or "dying" in front of the patient or to friends and medical staff when describing the patient's condition.

As a personal example, I had a friend and neighbor named Harry who complained of lower back pain. After numerous visits to the doctor, he was diagnosed with cancer of the spine. When talking to me about his medical condition he would refuse to use the word cancer instead he would quickly change subject and say, "I'm going to beat this thing." He knew he had cancer, but he would never address the word directly, even in the last days of his life. In the hospice view, facing the reality of death won't necessarily make it come sooner,

but if fears and worries can be expressed verbally, they can often be dealt with or diminished (Stoddard, 1991).

What is a Hospice

A hospice is an organization with specific services intended to relieve the varied symptoms of terminal illness. Some hospices are community-based home care agencies, others are departments or units in hospitals or nursing homes and some are independent live-in autonomous facilities. In a description of the different types of hospice programs available in the United States, Anne Munley found the following:

Currently, although individual types of hospice programs vary, there are at least five identifiable types of hospice programs in the United States: (1) the free-standing hospice that provides inpatient service along with home care; (2) the home health agency hospice; (3) hospice beds or a palliative-care unit within a hospital; (4) the roving hospice team working with dying patients wherever they are located; and (5) the hospice program with hospital and medical school affiliation (p. 32).

Hospice service is designed to be an overall team effort between the patient, the patient's primary physician and the hospice staff. The initial decision to place the patient in hospice service is given by the patient's primary physician upon the diagnosis that the patient's condition is terminal with a prognosis of the patient having six months or less to live. Once this diagnosis is made, the patient's physician can then prescribe hospice care. The patient's physician also oversees and authorizes the care the patient is to receive from the hospice organization.

Once assigned to hospice, the patient's overall medical service is directed by a staff physician in conjunction with the patient's personal physician. However, the specific medical treatment is planned and implemented by individual team members. The team is comprised of nurses, social workers, chaplains, therapists, nursing assistants and volunteers.

This team meets weekly, evaluating the patient and discussing the treatment plan in relationship to the patient and his or her present condition (Zimmerman, 1994; Zimmerman & Applegate, 1992). Different points of view provided by the different disciplines represented at

the weekly IDT meeting, is important for accurate patient evaluation. Each member of the team has his or her own unique perspective and can provide specific insights and solutions to a problem affecting the patient's overall condition.

Cohen (1984), in describing his research surveys sent to hospices throughout the United States, summarized hospice's service and organization as:

The typical hospice model represented by this survey is a non-profit corporation offering home palliative care, inpatient palliative care (either through their own facility's beds or through an arrangement with a local hospital or convalescent home), consulting and referral, bereavement follow-up, medical and nursing, counseling, spiritual, teaching and social services. Visiting hours and days are unlimited, with no age restrictions for visitors. The patient and family are the unit of care. The great bulk of the patients come from within a thirty mile radius and the population they serve is about five hundred thousand. Home care services are provided seven days a week, twenty-four hours a day for about thirty-five patients. The average length

of stay for inpatients is about fourteen days. There are about thirty volunteers in the program, who each contribute about four hours' service per week after about twenty hours of orientation and in-service training. The number of personnel are extremely varied, and no generalization can be made; however, usually a team is used consisting of the following disciplines: registered nurse, licensed vocational/practical nurse, social worker, physician, clergy, administrative personnel, and nursing assistants. The overwhelming number of patients are admitted with cancer diagnoses. More than half the patients are sixty-five years of age. Most of the inpatient beds are classified as acute hospital beds. Funding and revenues come from foundations, federal grants, state government, philanthropy, commercial insurance, Medicare, and Medicaid. Some accommodations are provided for overnight stay of patient's families. (pp.70-71, as cited in Stephenson, 1985)

Since this was written by Cohen over ten years ago, patients with AIDS now account for four percent of all admissions. In addition, in 1997, fifteen percent of the

hospice's in the United States are for-profit organizations, and there are approximately 2,800 hospice program compared to 1500 in 1985 (Stephenson, 1985; Hospice Fact Sheet, 1996).

Historically, the words hospice, hospital, hotel, or hostel were all used interchangeably. Etymologically all these words come from the Latin term hospes (Siebold, 1992) which means both host and guest. Ancient hospices offered more than just care for the dying; they also gave aid to the sick, the indigent, and the traveler/pilgrim.

For a detailed history of hospice see appendix B).

Webster's Seventh New Collegiate Dictionary (1969) defines hospice as: "lodging for travelers or for young persons or the underprivileged especially when maintained by a religious order" (p. 402). It hasn't been until the past 10 or 15 years with the resurgence of the hospice movement that our medical community has remembered the importance of the host/guest relationship.

In a recent definition, Steman's Medical Dictionary 25th Edition (1990) edited by W. R. Hensyl, defines hospice as:

an institution that provides a centralized program of palliative and supportive services to dying

persons and their families in the form of physical, psychological, social, and spiritual care; such services are provided by an interdisciplinary team of professionals and volunteers who are available at home and in inpatient settings. (p. 725)

In the past twenty-one years, there has been a big change in the definition and concept of hospice, perhaps a reflection of American society and its changing viewpoint on what and how the dying process should be.

Both Stoddard (1991) and Siebold (1992) agree that there are many reasons why American society treats death the way it does; one reason is the taboo against discussing death in daily conversation. The second is the American focus on youth, wealth and vitality to the exclusion of the aged, and the third is the Puritan view that losing control, power, vigor are undesirable human failings. Fourth is our loss of the richness of our personal relationships. Fifth and sixth is the materialism of American culture, and finally sixth is the loss of connection between man and his environment.

Definition of Terms

The following terms are defined for the purpose of clarity and understanding:

Community Hospice--Hospice care delivered to terminally ill individuals at their place of residence on an outpatient basis.

Death and dying talk--Any verbal communication about or concerning the patient, their diagnosis, care and treatment.

Field/hospice nurse--A nurse employed by hospice who visits patients at their place of residence.

Home Health Aids--Usually identified as CNA's, Certified Nursing Assistants, because of the patient care training program they attend.

Hospice Staff--This includes all employees that work at NC Hospice which includes, nurses, social workers, chaplain, medical record clerk, receptionist, volunteer coordinator, certified nursing assistants, and the pharmacist.

NC Hospice--The specific hospice where the participant-observations research was conducted.

Primary care giver--The individual who is designated in writing to provide care for the patient. It is usually the patient's spouse.

Research Questions

The following is a list of research questions this study attempts to address and answer:

1. How does verbal communication operate in the hospice nurse, patient, and primary care giver/family relationship?
2. How are terminally ill patients and their dying process discussed among the various hospice staff?
3. What are some of the speech settings for talking about death and dying and what are the features of those settings?

Organization of the Dissertation

Chapter two provides an exhaustive summary of the literature used in this dissertation. This includes previous research on health care communication, research on death and dying, hospice, and methodology.

Chapter three provides a detailed explanation of the methodological and theoretical assumptions used throughout this study.

Chapter four is a general ethnography of NC Hospice which provides essential background information for chapter five.

Chapter five is a ethnography of communication looking at two distinctly different speech events: the IDT meeting and the patient's bedside environment.

Chapter six is the conclusion which includes a brief review of the study content, implications and future recommendations.

Appendix A is the philosophy statement of NC Hospice.

Appendix B is a detailed history of hospice and of the hospice movement from ancient times until the present.

Appendix C through E are forms used at NC Hospice during the IDT meeting and referred to in chapters 4 and 5.

Appendix F and G are handouts used in instructing individuals about what naturally happens biologically to

the human body as death approaches as well as a list of seven indicators of death.

CHAPTER 2

REVIEW OF RELATED LITERATURE

Health communication, as a sub-discipline of the communication field, has been rapidly developing over the last 25 years. This is a new area of study for communication scholars, and, as such, it does not yet have all the answers or even all the questions. This is especially true when it is realized that the disciplines of psychology, psychiatry, sociology, anthropology, linguistics, philosophy and medicine have been studying health issues for longer than communication (Fitzpatrick, Edgar & Freimuth, 1992; Glenn, 1990).

While it is true that communication scholars draw from this interdisciplinary base of research they also put their own unique emphasis on it. Communication researchers who study health issues have tended to do so based on their usual research foci: from the point of view of compliance gaining, non-verbal communication, persuasion, verbal apprehension, communication styles, and uses and effects of mass communication (Fitzpatrick, Edgar & Freimuth, 1992).

These trends in communication research can be seen in research articles which focus on such topics as: communication and persuasion, communication and compliance, communication effectiveness, the health care interview, public health advertising campaigns, types and styles of social support and coping with bad news.

Health Communication Research

Academic research into death and dying issues has attracted attention from various academic disciplines; however overall, this research has gained very little attention from the communication community. In the past, the majority of research literature dealing with the topic of death has usually fallen within the domains of psychology, philosophy, medicine, geriatrics and thanatology. Primarily, this is true because many of the commonly studied topics about death for example, the fear of death, death anxiety, causes of death, studying the social distance toward the dying or even bereavement have not been common research topics for communication scholars (Thompson, 1989).

Research into death and dying often requires an individual emotional experience and one which requires

extensive field work. Many researchers are reluctant to do this type of research because of length of time needed to conduct field research and the emotional impact on the researcher (Nussbaum, 1989). Death is not an easy subject to deal with on a personal or subjective level, or is it easy to study from a scientific objective standpoint. This topic can be very depressing and uncomfortable for most scholars to research. It could be for these reasons alone that there have not been more in-depth studies of the subject.

Health Communication Literature

One of the most difficult communication situations that we face is talking to someone who is terminally ill. We usually feel awkward and do not know what to say or how the dying person will respond to our conversation. Miller and Knapp (1986) addressed this issue of communication with the dying by looking at various strategies for interacting with them. Self reporting techniques of ministers and hospice volunteers were studied to determine how they established effective communication with dying patients. As a result of

analyzing these self reports, three styles of communication interaction were determined.

These communication styles involved avoiding, confronting, and reacting to the situation. In the first style avoidance the dying individual is physically avoided, even talking about the impending death is avoided. Confronting strategies are used by care givers to try to get the dying individuals to talk about their present feelings, and their impending death. The third style reacting, is a mirroring strategy used by the care giver to determine how they should respond to the dying person (Miller & Knapp, 1986).

Following Miller and Knapp, and their study of communicating with the dying, Zimmermann and Applegate (1992) studied comforting strategies used among members of an interdisciplinary team of a hospice organization. These researchers examined person-centered communication, and how it relates to overall team functioning. The job of a hospice team is to provide comfort and support to terminally ill patients and their family. However, almost daily members of a hospice team are exposed to various levels of emotional distress. The focus of this study is on the various communication strategies used to

deal with these stresses on the team and between members, and those individuals it attempts to assist.

In a later study, Zimmermann (1994) identified relationships in social construct systems of individual hospice interdisciplinary team members. She also looked at communication and satisfaction within team operation. The results were consistent with previous research done on this topic and also gave insight into the interpersonal construal process.

Another focus in health communication is communication and social support. The study of comforting communication provides an insight into the study of social support communication with the focus on what is being said. Burleson (1990) suggests that by using comforting strategies, social support is provided to others. In a 1984 article, Burleson defines comforting communication as, "the type of communicative behavior having the intended function of alleviating, moderating, or salving the distressed emotional states of others...the management of everyday disappointments and hurts" (p. 64).

It is researchers such as Burleson (1984), Zimmerman and Applegate (1992), and Miller and Knapp (1986) who

state that affective communication between terminally ill individuals can better enable them to deal with their illness, treatment, impending death and effect a positive death experience. In a 1987 article in Death Studies, Nimocks, Webb and Connell presented a conceptual theory and path model of communication involving the terminally ill. The theory is based on the assertion that communication influences the quality of a death experience and that favorable communication can be an essential element for a positive death experience.

Some illnesses, especially those chronic, or terminal in nature, can often isolate and stigmatize the patient. In a paper on intergroup self-stigmatization, Hanwood (1995) looks at the claim that dying individuals, older adults, and the mentally ill are stigmatized because of their group membership. He found that being stigmatized as a member of that intergroup while being a disadvantage can also be advantageous because it enables the membership of that intergroup to talk on a relational, personal, or social level.

Death has a definite cultural stigma in our society. For most people, death as a topic of discussion is an

extremely uncomfortable and inappropriate subject to talk about in everyday general conversation.

In an 1993 article, Kreps looks at death from a verbal communication point of view. In his article, he discusses why people are so hesitant to talk about death. According to Kreps, they do it either out of fear of facing their own mortality or by just trying to avoid the inevitable, which is death. In addition, we avoid talking about the subject of death directly, and instead use many colorful euphemisms in describing death and dying in general.

This avoidance of communicating about death has social ramifications in that it perpetrates the many fears and mythologies that American culture holds about death (Kreps, 1993). Because Americans avoid death by not talking about it, they do not prepare for it in their own personal lives. It is because of this lack of individual preparation that Americans have trouble giving understanding and support to those individuals who are either in the process of dying or for those friends and family who are grieving for the dying and the deceased (Kreps, 1993; Miller & Knapp, 1988).

While not directly studying dying and death issues, the study of communication about serious illness and diseases that can lead directly to death is an area of study that communication scholars have given much attention. Cancer, especially breast cancer and the AIDS/HIV virus are the two major health issues of the 80's and 90's that are being addressed in the health communication literature.

There was a time, not too long ago, when individuals who had cancer told very few people that they had it or that they knew someone who had cancer. During this time, there was a definite social stigma attached to having cancer or a terminal disease (Glasser & Strauss, 1965; Hanwood, 1995).

In this decade, contracting the AIDS/HIV virus has the same stigma. It is a disease that, like cancer, carries with it an extreme negative stigma. Many individuals are reluctant to even talk about AIDS/HIV much less admit that they know someone who has contracted it.

Generally, Americans do not want to talk about these diseases, the causes, the treatment, the cure and especially the ramifications. These diseases carry with

them not only medical and psychological ramifications but cultural and social ones as well. Some implicitly fear that, if they talk about death or any of these chronic diseases that they will get them (Hinton, 1980; Harwood, 1995; Eggerman & Dustin, 1985-86).

In addition to the fear of AIDS/HIV, cancer is one of the most feared diseases of the past 50 years (Cherry & Smith, 1994; Cline, Johnson, & Freeman 1992; Edgar, Freimuth, Hammond, McDonald & Fink, 1992; Gantz and Greenberg, 1990; Greene, Parrott, Serovich, 1993; Hammond, Freimuth and Morrison, 1990; Ling, 1989; Nussbaum, 1989; Perloff and Ray (1991; Reardon, 1990; and Zook, 1993). I cannot think of a more dreaded phrase coming from a doctor or nurse than, "I'm sorry, but you have cancer, or I'm sorry, but your child has cancer." Identifying various strategies used in telling individuals that they have cancer or strategies used in helping individuals cope with cancer has been the emphasis of health communication research studies done by Sullivan & Reardon (1986), and Gotcher & Edwards (1990). In both studies, the authors show that patients and family members demonstrate an increased coping ability and communication satisfaction associated with the

quantity and quality of information received, and questions answered by the physician or health care professional. In addition, these studies show that communication generally aids in reducing overall fears and stresses associated with the disease of cancer.

Nonetheless, for whatever individual reasons, a large number of cancer patients are becoming reluctant to comply with their treatment regimens. Evans and Clarke (1983) report on this phenomenon, and on what happens when cancer patients and other chronically ill patients fail to get well, either as a result of the patient's abandoning treatment or when treatment itself fails to cure. The reasons that some patients fail to follow treatment are not known. The existing theory is that the patients lose self esteem as a result of the physical side effects of chemotherapy. Both Evans and Clarke (1983) believe that by improving communication with the patient and by providing support, patient treatment compliance would increase.

The use of effective communication was also found to be extremely important for individuals adjusting to cancer (Gotcher, 1993). This is especially true when communicating with the patient's family. Strong

supportive communication among family members has resulted in overall better adjustment for all involved, and allowed the patient to manage the cancer in a less stressful manner.

Hinton (1980), in a study of patients in the later stages of terminal cancer, investigated how patients and their spouses shared or withheld information concerning awareness of dying. Some patients who were aware that they were dying shared this information with their spouse while other couples did not share this type of information with each other at all. He concluded that there is an advantage to the sharing of information between the dying patient and his or her spouse, but that this style is not the best style of communication for all couples.

Additionally, doctor-patient communication is important because of the ramifications to patient treatments. This communication is especially critical in serious and life threatening medical situations. A study by Hines, Moss, McKenzie (1995) looked at how doctors communicated with their patients who were facing life-threatening illness and needed to choose between

additional medical treatment or impending death (Hines et. al., 1995).

In a companion study, Hines, Babrow, Badzek and Moss (1996) used Babrow's problematic integration theory which analyzed end-of-life decisions made for elderly dialysis patients by their doctors. They concluded that both the patient and the doctor tend to avoid discussing life-threatening illness and its significance until they have to which usually occurs when the patient has an acute negative symptomatic response.

In a thought provoking essay, Teresa L. Thompson (1989) discusses communication and dying at the end of a life-span. In the essay, the author discusses such issues as: Should dying patients be told that they are dying, overall communication with the dying, interpersonal communication and coping with dying, how dying is talked about, death and helping children talk about it, the family members of the dying, and the overall communication process between dying patients, their family members and the health care providers (Thompson, 1989).

Related Thanatology Literature

The most contemporary, and extensive literature dealing with issues of dying comes from the disciplines of psychology, sociology, medicine and research in ethics concerning death and dying. The fields of sociology and psychology have directed much of their research efforts to looking at the patient-doctor relationship, the ways a patient arrives at treatment decisions and physician's disclosure of life threatening illness to his or her patient (Broland, 1993).

Eggerman and Dustin (1985-1986) studied the attitudes terminally ill patients and physicians have towards death. They looked at communication that occurs between dying patients, interning medical students, and the primary family physician. They found that all of the family physicians in their sample and 93 percent of the medical students believed that terminally ill patients who request information about their present physical condition have an "unequivocal right to know" and should be given that information.

These researchers further concluded that 76 percent of the family physicians and 65 percent of medical students believed that patients should be told about

their terminal medical condition, voluntarily. The study also found that 67 percent of the family physicians believed that the telling of bad news to the patient should never be delegated to the nurse or to someone else. They believed that it is the sole responsibility of the patient's physician.

Smith (1985) examined the role which communication plays in the treatment of cancer and specifically in the participation of family members and health care providers. Often health care professionals who deal with chronic and deadly diseases tend to perceive their role as one of solely controlling and/or curing that disease.

Smith (1985) argues that as a result of this belief, medical personnel often ignore the patient, and any contributions the patient can make towards his or her treatment. This can result in the patient and family members feeling, not in control, left out of the decision making process, helpless and consequently result in a negative effect on the overall treatment effort of the patient.

Determining how much information should be communicated to the cancer patient and when it should be shared is a difficult issue for the physician. Prior to

the 1970's, the cancer patient's desire for information about their medical condition and the physician's willingness to communicate that information to them, was a strongly debated issue throughout the medical community. Many physicians for whatever reasons did not want their patients to know that they were terminally ill and had a very limited life expectancy.

Further, Smith (1985) recounts that as recently as the 1960's, doctors routinely refused to tell patients that they had cancer, let alone that they would die of it. However, of late, the tendency of health care professionals is to communicate the truth to their patients. It must be remembered that the expertise of the physician is in the physical healing and saving of lives, and not in easing the emotional pain of those near death. So from this perspective, the physicians' reluctance to communicate with their patients about these issues can be understood.

Shute in the U. S. New and World Report, reported that a 1996 study from the University of Minnesota, showed that many doctors had no clinical or ethical framework to help them deal with dying patients.

In a description of a daughter talking about the dying of her mother, Smith (1985) describes the way in which failure to communicate between the doctor, patient and patient's family can negatively affect the course of a terminal illness. The following passage illustrates the importance of accurate, candid communication between the physician, the patient and the patient's family.

My mother died 5 years ago of brain cancer. She was hospitalized on the 26th of October and died the 17th of January...she was 68 years old...Then one night, she was paralyzed on her left side and she lost her equilibrium when she attempted to walk...Then the tests began and the K-rays...There was no immediate diagnosis suggested, just the insecurity, the utter confusion. What did she really have? She asked me: "Am I going to die?" I answered that she was in good hands and that they would do everything possible to help her recover from this illness. The doctor told the family that it might be arteriosclerosis or a tumor-benign or malignant--that's the question.

Time passed; the visits, the members of the family and friends kept coming in a steady stream.

It was like a reunion around her bed. One Sunday the whole family was gathered together, and she spoke and thanked us all for being there; she cried at the end saying that she would like very much to hear the Ave Maria of Schubert. Since she had always told me that, that was the music she would like to hear on her death bed, we children were stunned and told her that it was not a question of dying, but of getting better...I felt that she had every reason to be thinking about her death, but none of us dared to say to her that we, too, were thinking that perhaps she was going to die. But we all thought it...finally the diagnosis was communicated to us by an intern...He told us that there was a tumor and that it was necessary to operate. My father, my husband and myself and one cousin was there...He said that the chief of surgery would speak with mother about the operation...When I went to see my mother the next day, I asked her if the doctor had spoken with her and told her that they wanted to operate...She didn't respond. I asked her again.....she finally answered: "All right! They're going to operate, that's that"

....Some days later I asked her, "You are not talking to me?"..."Do you think that you are dying?" Complete silence...I sensed that she was very depressed, in great pain...

After the operation...I tried to find out how everything had gone in the surgery...I couldn't get any details from the staff and was unable to find a single doctor. Someone gave me the telephone number of the surgeon. I called him...that evening...In a trenchant tone of voice...he told me: "the tumor was enormous and badly situated; we had no choice but to open and immediately close."...The "Good night, Madam" of the surgeon was rapid and striking: a 30-second message that basically said "your mother is lost." I would have liked to have known what to anticipate about the course of the illness, what attitude to take, what to say, what to do. I felt the doctor just did not want to be involved any further; this poor sick woman had been reduced to an object. The family was the one that was left to be involved with her. (p. 203-204)

In discussing patient-physician communication and how it has improved over the past 30 years, we must look

at the concept of "informed consent" (DeSpelder & Strickland, 1983; Kasterbaum, 1981; Kreps, 1988; Smith, 1985). Informed consent is the legal right of a patient to have complete disclosure about the diagnosis of his or her illness and be told of the various options available for treatment. Informed consent has been established by the government to ensure the rights of patients and their ability to know and to choose for themselves. This right enables the patient and physician to establish open communication and a subsequent partnership in the management of the disease.

Communication can be so many things to so many people, and it can change given different conditions, different situations and different environments (Burgoon, Callister & Hunsaker, 1994; Gotcher, 1993; Hinton, 1980; Lane, 1983; Miller & Knapp, 1988; Thornton & Kreps, 1993; Reardon, 1988; and Zook, 1993). Just as there are so many ways of communicating, there are also many ways of listening. For example, when someone is dying, how do you know how to talk to them, or how to relate with them?

In a philosophical treatise on communication and the dying, Lukeman (1982) states that first, outsiders need to avoid establishing labels and trying to understand the

situation from an intellectual manner. He says, that, "Instead, simply be there and be open, accepting, and fully available to whatever is going on" (p. 66).

When addressing the question of should health care professionals and family members tell the truth to dying patients, Lukeman (1982) states:

The dying know that they are dying. You are not asking about the dying, you are asking about yourself. The real question is not, "Should I tell the truth to the dying:" The real question is, "Am I willing to openly face and deal with what is going on?" (p.66)

He says that when all is said and done, communication must be an honest, open exchange between communicators. In the conclusion of his article, Lukeman says all posturing and pretense needs to be dropped for it means nothing to the dying. "The art of truly communicating is the art of getting out of the way, of not being afraid, of allowing ourselves to be who we truly are and allowing the other person to be too" (p. 69).

In trying to understand how the dying and the dead are treated in hospitals and in nursing homes, we need to

look at two classic ethnographies that deal with the subculture of the death and dying in hospitals and nursing homes as well as those who attend them. These monographs are as follows: Passing on: The Social Organization of Dying (1967), by David Sudnow and Living and Dying at Murphy Manor (1975), by J. F. Gubrium. Sudnow a sociologist, was interested in how dying people are classified in two different hospital settings: a private hospital and a county hospital.

In his study, Sudnow looked at death not only as a biological event but as a sociological event as well. He discovered that once patients are classified as dying, they are stigmatized by the hospital staff and treated in a certain manner differently from other patients. Once the status of "dying" or "dead" was assigned to a patient he or she was given different services than those patient's who were not labeled "dying or dead."

Sudnow (1967) observed that in the county hospital during the evening and under certain situations if the staff thought that a newly admitted patient was dying they would leave the patient in the laboratory or storeroom to die so that the staff would not have to make

the bed, or admit him or her to a room before the relatives and doctors arrived (p. 63).

If the staff determined that an existing patient was going to soon die, to avoid touching a dead body, they would force the patient's eyes shut, insert dentures, diaper the patient, change the bed and bind the patient's legs together. All these tasks are normally performed once the patient dies. For the staff, it was physically easier, more expedient and less distasteful to perform these tasks on a living patient instead of a deceased one (Sudnow, 1967).

If a patient died while on the ward, the staff would go to great lengths to disguise the death from the other patients on the ward. This would include talking to the dead body as if he or she was alive, wheeling the dead patient off to X-ray (Stephenson, 1985) and even using their own bodies as a visual shield thus blocking the corpse from the view of the rest of the ward (Sudnow, 1967).

Sudnow's ethnography describes the conflict between the function of hospital bureaucracy and human needs. The results being that the needs of the patient are not as important as the bureaucracy, and within this

bureaucracy dying patients do not have a high priority.

Gubrium (1975), in a study of a nursing home, described what daily life is like in another type of bureaucracy. In this research, he describes the attitude of the nursing home staff as being one of care taking as opposed to care giving. Their focus was on the tasks of care giving such as washing, feeding, changing linen, while neglecting the human element of compassion, modesty and respect. As Gubrium states, "Making peace with hopelessness is a difficult task, and it is the one that people encounter in breaking up a home to take up life at Manor" (p. 83).

The floor staff of the nursing home, Gubrium states, is more concerned with what he calls "bed and body work" which is day to day duties performed by the staff that keep the individual's patient alive. This is done in contrast to the overall concern for the individual emotional and personal needs. In the context of a nursing home, it is the 'bed and body work' that the staff performs towards keeping the patient functioning biologically that is important. Once entering the nursing home, the individual gives up all self-control and autonomy and quickly becomes assimilated into the

routine of the nursing home institution . According to Stephenson (1985), studies have been done showing that life expectancy drops once an individual enters a nursing home.

In a 1965 classic monograph, sociologist Barney Glaser and Anselm Strauss studied attitudes toward death within a hospital setting. They focused on the interaction that exists between dying patients and the hospital staff. They found that patients who were dying in the hospital were abandoned by staff and left to deal with their physical condition without much support. The closer the patient was to death, the less his or her physician visited, and the slower the floor staff was to answer the patient's request for aid. Glasser and Strauss were less concerned with the death of the patient than with the process of death and the contexts in which it occurs. They asked questions from a sociological perspective such as:

If increasingly Americans are dying within medical establishments, surrounded more by nurses and physicians than by kinsmen, then how do these representatives of the wider society manage

themselves and their patients while the latter are dying? (p. viii)

Using a sociological framework, they asked questions concerning the hospital's organization, forms of social action, both transitory or permanent, that occurred while handling the dying individual. They were also interested in what the social consequences were for the hospital, its staff, and for the patients and their families Glaser & Strauss (1965).

In answering these research questions, they used the theoretical scheme they called "awareness context" which refers to, the distribution of knowledge among the staff that the patient might die, (Glaser & Strauss 1965, p. xi, 10). In the organizational setting of the hospital, it can make a difference who knows what in order to understand, "whether people can die socially before they die biologically, and what this means for human relationships." (Glaser & Strauss 1965, p. X, 6).

Different types of awareness contexts exists according to Glaser and Strauss. The first is closed awareness when the staff knows the condition of the patient and the patient does not. A second type is

suspected awareness which occurs when the patient begins to question information told to them. Mutual pretense awareness is a situation when everyone knows the patient's physical condition, but no one wants to discuss it. In the fourth, open awareness, all parties know everything and speak openly about it (Glaser & Strauss, 1965, p. 10-11).

All three of these last studies, by Sudnow, Gubrium and Glaser and Strauss look at social interaction in the context of institutionalized, infirm or dying patients. Institutions, both hospitals and nursing homes, are economic entities and for them, efficiency, profit and the bottom line can be more important than the needs of their patients. These studies show this by looking at the institutional bureaucracy, the members of that bureaucracy, and how these members behave in ways which reflects, not the needs of the patients but rather the needs of the institution (Stephenson, 1985, p. 60-61).

In American society, dying and death has become the domain of hospitals, nursing homes, or hospices (Stephenson, 1985). Sudnow, Gubrium, Glasser and Strauss all conducted studies that dealt with the subject of death and dying in the environment of the nursing home

and hospital institution. The common theme of these reports revolve around the staff and the patients. These reports can be read as ethnographies of communication, even though they were not composed that way.

Literature on Hospice

The concept of hospice as being a place for the poor, the sick, the dying, and the indigent has been around for many centuries (Stoddard 1978). Today, hospice means more than a place for the terminally ill to die, it also is a philosophy and a way of dying (Kasterbaum, 1981; Stoddard, 1978; Hastings, 1993; Narasi, 1992). Fifteen to twenty years ago, the term hospice was not even in the dictionary. Today there are profit and non-profit hospice organizations located all over the United States (Kasterbaum, 1981).

It was in the 1960's and 1970's that medical professionals such as Dr. Cicely Saunders in Great Brittan and the psychiatrist Elisabeth Kubler-Ross in the United States began to write and lecture about the dilemma of dying individuals (Kasterbaum, 1981; Kubler-Ross, 1975, 1978; Stoddard, 1978). Since then, death has been taken "out of the closet" and has become a

recognized domain for social and scientific research. The study of death and dying is called thanatology, and this study has its own professional journals such as Omega, Death and Dying and Death Studies.

With the topic of death and dying becoming an accepted course of study, the hospice movement began to grow. According to Stephenson (1985), De Spelder & Strickland (1993), and Narasi (1992), the goals of hospice are to let patients be free of pain, manage disease symptoms and to meet social, psychological and spiritual needs of dying individuals and their family. This assistance can take place either at home or in a specially designed institutional setting.

Hospice care is a unique health care environment with the focus on palliative care for the patient and not curative care (Smith, 1985; Stoddard, 1978; Beresford, 1993). Palliative care emphasizes the treating of both the symptoms and the pain associated with certain terminal illnesses (Smith, 1985). Some of the characteristics of a hospice stated by Du Bois (1980) are the following:

Expert, multiple disciplinary management of pain and other symptoms.

Reasonable fulfillment of individual lifestyles.

The provision of care and consideration to all those affected by the patient's death, including the incorporation of family members into the decision-making process, even when special education may be required.

Continuing follow-up care for the bereaved.

Special care and concern for the staff. (p. 69. as cited in Stephenson, 1985)

The basic principals held to by hospice are that terminally ill individuals need to have dignity, individuality and humanness as a factor in their dying process (Narasi, 1992; Bresford, 1993; Stoddard, 1978). By allowing dying patients their humanness and allowing them freedom to make their own decisions, the physical, emotional and psychological suffering brought on by the terminal disease can be reduced (Stephenson, 1985; Anderson, 1992).

Ethnographic Literature

Further discussion on the literature of ethnography and ethnography of communication will be discussed in the next chapter, chapter three.

Summary of the Review of Literature

The study of health care provides a new setting for researchers to study communication. Using traditional research topics such as communication satisfaction, patient compliance, persuasion techniques and patient interaction, communication researchers can focus on the many problems that are indigenous to a multifaceted health care community.

Medicine has changed over the past decade: Doctors, and the patients that they serve, are no longer acceptant of one way communication exclusively coming from the physician. Patients are beginning to ask questions of their doctors about their disease and prognosis. They are also taking responsibility and demanding to have a part in the development of their treatment program.

Some scholars in the health communication community have expanded their perspectives of what health communication means to include the terminally ill especially those dying of HIV/AIDS and cancer. Both diseases are acute and can be fatal and both diseases have received much publicity from the media and great concern from the American public.

The topic of death in the professional health care literature was virtually non-existent prior to the early 1960s. With the publication and lectures of Dr. Kubler-Ross and her work, death and dying from the patient's point of view, and the work of Dr. Saunders, who established the first model hospice in England, this began to change for the better. Initial research literature that dealt with death and dying issues was encouraging but tended to emanate mostly from the social sciences.

The hospice concept, once it reached the United States in the late 60s, early 70s began to question the traditional way the public and the medical community looked at death and dying. Hospice provided an alternative to dying alone, in pain, and without human dignity.

Using the hospice philosophy, terminal patients can gain control of the otherwise uncontrollable medical situation of dying. Authority is given back to the patient and to the family. The doctor is still involved but not completely in control. What was once a medical dictatorship is now a medical democracy and a team effort.

CHAPTER 3

METHODOLOGY

The study of the terminally ill and how they talk about death and dying can contribute much to the field of communication. Death is inevitable: it happens to all living organisms eventually. However, the settings, circumstances, environment, and causes differ, and these differences can give communication scholars an abundant environment for study. However, since the research is difficult and taxing for both the researcher and the person or persons being researched, this can cause restrictions in the methodology available to the health care communication researcher. It is because of these reasons that I chose these particular methods and theory.

Dying is personal, emotional and a very private affair, and no matter how many people are with us when we die, we still die alone just like we come into the world. It is for this reason that it is important for the communication researcher studying the terminally ill to remain as unobtrusive as possible.

When researching this topic for this study, I chose a method which allowed me to be a part of the activity but also to remain at a distance from it. I used a multi-method approach which allowed me to observe and describe what was going on around me in any given situation and to get a better perspective of the phenomenon I was studying.

The point of view that I use examines the data ethnographically in a fashion informed by Agar, (1986), and Leiter, (1980). Additionally, I use the phenomenology of Schutz, (1962) and Husserl (1960), the ethnomethodology of Garfinkel (1967), Sharrock and Anderson (1986), Heritage (1984), the dramaturgical perspective of Goffman (1959) and the ethnography of speaking of Hymes, (1962), Philipsen (1972, 1976), Salzmann, (1993), Carbaugh (1995) and Duranti (1988). These perspectives on qualitative data gathering and interpretation provide the framework for this research. Each of these perspectives is linked to the others conceptually, and they all share certain conceptual approaches (Borlan, 1993). Together they provide the direction for the research questions initially asked and for the analysis of the data.

I wanted the overall focus of the research to be grounded in the death and dying experience of NC Hospice. To achieve this objective, I chose a qualitative method and theory to gather and analyze my data. Ethnography as a data gathering method was used initially because I wanted to describe the daily experiences of the membership of this specific community hospice. Because it allows the researcher to view and describe social communicative competence I used the ethnography of speaking as an additional method. These descriptions will take the form of describing the verbal talk and the setting for verbal interaction that is used by its members, especially the various communication processes used in the nurse-terminally ill patient-family triad as they interact with each other.

Ethnography

It is the job of the ethnographer to describe this common-sense knowledge objectively from the point of view of a member of that society (Agar, 1986; Leiter, 1980, p. 86-87). In addition to a description of that society, an ethnographer who pursues an ethnomethodological interest attempts to describe how that society operates.

Descriptions of the social reality are made by the researchers based on the researchers' sense of social structure, common sense knowledge, and practical reasoning.

Some characteristics of the ethnographic approach to research are that the researcher uses a natural setting to work in, the research is descriptive; there is concern with process rather than just results; analysis of data tends to be inductive, and "meaning is the major concern of this method" (Brolan, 1993, p. 54-55).

The data gathered tends to be detailed, rich and descriptive in nature. The research questions developed are acquired from field work conducted in the environment in which the people being studied live and work. These questions are not exposed to deductive or hypotheses analysis and testing, but rather to theory development based in the lived experience.

Ethnography of Communication

In chapter five and six I present accounts and analysis of material that attempts to provide an ethnography of everyday speaking in a community hospice.

In its contemporary form, according to Salzmann (1963), the ethnography of speaking (or ethnography of communication: either form is correct) can be traced back to anthropologist and linguist, Dell Hymes in a 1962 article he wrote titled, "Ethnography of Speaking." This article gave scholars across disciplines a methodology and a model of how individuals construct shared meaning from sociocultural and personal experience (Fetch & Philipsen, 1995, p. 263).

In the field of communication, one of the first researchers to use ethnography of speaking as a research tool was Gerry Philipsen who wrote his dissertation on the speech behavior in an urban neighborhood he called, "teamsterville" (Carbaugh 1995). According to Carbaugh:

Philipsen formulated the approach as a way to analyze communication as a cultural resource, with others in the field using this approach, for example, to investigate communication among Vietnam veterans (Braithwaite, 1990b), among Chinese (Chen, 1990-1991; Garrett, 1993), among Appalachians (Ray, 1987), and among church members (Sequeira, 1993).

Many studies in EC have been conducted in the United States, but also the approach has been applied

widely in a variety of other countries, for example, in Columbia (Fetch, 1991), Israel (Katriel 1986 1991), and Finland (Carbaugh, 1993). Additionally, EC has also been used to conduct cross-cultural analysis of silence (Braithwaite, 1990a), conflict management (Shailor, 1990), and terms for talk (Carbaugh, 1989). EC has been productively used, therefore--within and across cultural communities--as a way to apply and develop communication theory. (1995, p. 269)

Generally an ethnography of speaking studies language use, and ways of speaking, as it is used in the everyday life of a particular speech community (Carbaugh, 1995; Duranti, 1988; Fetch & Philipsen, 1995). Ethnography of speaking uses as its method ethnography, with additional techniques from the developmental pragmatics, conversation analysis, poetics, and history (Duranti, 1988, p. 210).

The ethnography of communication approaches communication on the sociocultural level. Interpreting patterned verbal communication and it's meaning from the perspective of the specific culture from which the individual speaker belongs (Carbaugh, 1989; Duranti,

1986; Fetch & Philipsen, 1995). Through the use of participant observation, discourse is studied in situ, looking at how talk is organized and conceptualized within a particular speech community (Carbaugh, 1989; Fetch, 1994; Fetch & Philipsen 1995).

Introduction to the Setting and the Subjects

The primary setting in which the research was conducted is a moderate sized community hospice in a medium size college town located in the south central mid-western United States. The patient population varied throughout the study from 25 to 40 terminally ill patients. This community hospice has a total staff of about 20 employees. It is accredited by the National Hospice Organization, the state and Medicaid and Medicare.

The principal subjects of study were selected staff members, primary care nurses, patients under their care and their family members and friends. I received in writing a letter from NC Hospice* giving me permission to perform research at their facility, and approval from the Office of Research Administration from the University of

Oklahoma to conduct research using human subjects (refer to appendix H for the approval letters).

During the period of the primary research, a total of seven field nurses, two home health aids, two chaplains, three social workers, six office staff, one pharmacist and over 30 terminally ill patients were observed and/or interviewed over the course of six months, during which the primary research was conducted.

Among the methods particular to qualitative research used in this study were casual conversation, participant-observation, unscheduled-unstandardized interviews, scheduled-standardized interviews, document reviews and appropriate data analysis. In addition to participant-observation research conducted at NC Hospice, (the research site), the researcher had previously worked there for the preceding year as a hospice volunteer assigned to a specific patient. This experience had a bearing on the research, especially in the early development stage.

Participant-Observation and Interaction

For the first two weeks of on site research, the researcher learned the routine of the NC Hospice

administrative staff. I spent the time observing, trying to fit in to the surroundings, be inconspicuous and engaging the staff in casual everyday conversation. This time initially spent in the office helped to develop relationships with the various staff members which was necessary in successfully performing this research. This initial informal interaction was necessary so the researcher could get to know the staff and the staff could get to know the researcher on a personal level. Trust among the staff members was a very strong element in this setting. This time also enabled the researcher to study NC Hospice from the point of view of the administrative staff.

Extensive participant-observation occurred mostly with the field nurses, patients and their families. This was central in developing the theoretic arguments concerning the nature of communication about terminal illness, the nature of the 'work' of dying and the experience of the nurses in dealing with the terminally ill patient and their family. In order to obtain this level of understanding, regular observation-participation in the activities of the subjects and the interactions of subjects with one another as well as with the researcher,

were required. This was accomplished at the hospice office, in the vehicle traveling to and from a patient and at the patient's home or place of residence. Particular attention was given to observing the verbal interaction between the staff at the required weekly meeting, to the nurse during the visit with the patient, patient's family and with the patient's primary care giver.

Participant-observation research places the researcher in a unique position to "see one type of interaction" and "hear another." It permits some access to what Goffman (1959) calls front and back regions (p. 59).

Nurses, staff members, patients and their families would interact and talk with each other on one level and with the researcher on another. This researcher at times would seem to, "blend into the woodwork" sometimes intentionally and sometimes unintentionally. Being in the background of the action enabled the researcher to ask questions about whatever seemed to be of significance to the actors.

In talking to the nurses in the car traveling to and from a patient's place of residence, they would clearly

say what it was they were thinking, what they were doing, and why they were doing it. The nurses would respond openly to questions from the researcher about what he had seen and experienced during the nurses visitation with the patient. This interaction was recorded using a tape recorder when possible and in extensive field notes.

Unscheduled-unstandardized re-occurring interviews were held chiefly with the chaplain, volunteer coordinator, and social worker, although other members of the staff were interviewed throughout the course of the study. These interviews with the chaplain, volunteer coordinator and social worker were repeated at various times and helped in the discovery of recurring themes and in answering questions about the patient, the death experience and its consequences to the patient and the family. These answers provided more than just a medical orientated prognosis; they told about the 'humanness' as well as provided an insight into the 'work' the patient and those surrounding the patient perform, as part of the dying process.

The document review was another important aspect of the research. Documents concerning the patient contain more than just medical data recorded by the doctor and

nurses. They also included various types of social information about the patient and family, their interactions and possible dysfunctions. Included were reports made by the social worker, chaplain, and hospice volunteer. These documents provided information on who does what, who says what, what is not being done and how this all relates to the patient's illness and the reaction from the family. Also provided were insights on differing points of view from the various team members.

Summary

In conclusion, this research is an ethnographic quantitative study of hospice nurses, their patients, the primary care giver and the family over the course of the terminal illness, ending with the death of the patient. The basic organizational framework for this study is based in qualitative philosophy, and it is expressed in ethnographic description. The methodology used, stresses the emergence of social theory from the data of the experience, as well as the meaning of the sociolinguistic interaction to those actors who are involved. Qualitative research does not test and verify hypotheses nor is it to be generalized to other situations. It is,

however, science because it is a rigorous and systematic empirical inquiry based in the "thick description" (Geertz 1972) gained from extensive field work.

CHAPTER 4

THE SOCIAL SETTING: AN ETHNOGRAPHIC ENQUIRY INTO A COMMUNITY

A few years ago after a long intense academic emersion in graduate school, I decided to seek some relief by signing up to become a hospice volunteer. I went through the training process and then, after a few weeks, the volunteer coordinator matched me up with a terminally ill patient. During training, we were taught that, in addition to being a companion for the patient, we were also an advocate for the patient, looking after his or her interests.

My patient was a male widower in his early 80's, who lived in a local nursing home. He was alert, interested, and very lonely. His wife had died a few years before, and they had shared a room in the same nursing home. When I met him, he had been a hospice patient for over a year and was diagnosed as terminally ill with prostate cancer and congestive heart disease. I spent about 2 to 4 hours with him every week and during that time we talked or, should I say, he talked, and I listened. Over

the course the year I was his hospice volunteer, (my relationship to him changed from being just an assigned hospice volunteer to that of being a friend and confidant). He began to tell me matters about his personal life that he did not even tell his three sons.

It was during this part of our relationship that I began to experience both his living and his dying through his eyes, the eyes of an insider. For a year, I sat and talk with him in the nursing home; he in the bed and me sitting next to the bed. As I sat with him I began to be aware of the common everyday intrusion into his life by doctors, nurses, various nursing home staff, his family and even from hospice personnel. I also began to notice how these events affected him and how he dealt with them. It was these events that led me to begin observing with an ethnographic eye, his social and verbal interaction in the nursing home setting.

Therefore, it was this set of circumstances that led to my interest in studying hospice. At first, I was unsure of whether I should focus primarily on hospice or on nursing homes, because I was in a position to observe both. I knew that there were previous studies of nursing homes, but I found few sociological focused studies of a

community hospice. It was when my patient was close to death that I decided to research the community hospice where I was volunteering. After some library research, I found that there was very little research devoted to communication about death and with the dying, and especially a void in research about communication with the terminally ill hospice patient.

I decided to study the particular community hospice (called NC Hospice in this study) for a variety of reasons. First, I had already established a personal relationship with some of the staff members. Second, they were comfortable having students in and around the office because of an existing internship program in nursing and social work. Thirdly, the location was close to my place of residence, the university library and my place of employment which are important considerations because this research was self-funded.

The ethnographic description presented here provides a background perspective for chapter five which will focus on the sociolinguistic interaction of a group of health care professionals employed at NC Hospice. In describing the social setting of NC Hospice, I first established a framework in which to understand the

various verbal interactions that occur among NC Hospice nurses as they communicate about and with terminally ill patients.

It is through the use of this descriptive ethnography that an 'ethnography of speaking' will be developed. This ethnography of speaking studies language use as revealed in the everyday life of a particular speech community (Duranti, 1988). This ethnography of speaking describes the settings, rules, functions, and situations involved in speaking about terminally ill patients.

The Setting and Subjects

It is important to place this research in the context of the sociocultural and linguistic community in which it is a part. The community hospice where the research was conducted is located in a medium-size town in central Oklahoma just south of the state capitol: Oklahoma City. The population of the town in which it is located is primarily Caucasian; however, there is some ethnic and racial diversity due to the large state university located in the town.

The community hospice where the study was conducted is just one of many hospices in and out of the state, which is owned and operated by one independent for-profit corporation. These hospices are, for the most part, situated in medium-size towns in the central and south central part of the state. From these locations, the hospices can reach out and provide hospice service to major and minor cities, and to many smaller rural towns and communities in the area.

Within the state, according to my informants, there are approximately 10 differently owned and operated hospice organizations. Throughout the research, there were some indications that there was competition between these hospices for patients, at least in the smaller cities and towns in the state. Some are operated for profit while others are non-profit. The hospice I researched was classified as a "for profit" organization. While there is not any difference in service provided to the patient in a "for profit" or "non-profit" hospice, the difference is in how the business is registered with the state and the tax revenue considerations that it receives.

Demographics

The population in this study reflected generally the demographics of the town and of the surrounding area. Almost all of the 40 patients and their families were Caucasian, as were the nurses and the hospice staff with the exception of one black home health aid and one Latino LPN nurse. Many of the patients, although white in complexion, claimed that they had some Native American blood and were "on the tribal rolls."

The majority of the patients observed during this participant-observation study were over the age of 60, with only a few of the patients in their 20's and 30's. A few weeks before I began my research, there were two children under the age of 3 years old that had been on hospice service and had died.

In any given week of the research, the majority of the patients were females comprising up to 75 percent. The rest of the patients were males, with a population never going past 30 percent. The majority of the patients observed resided at their homes in a residential location with their spouse, family, or in an extended family. Only a small minority of the patients resided in nursing homes or health care facilities. Some of these

nursing home patients resided in these facilities only temporarily for short term care and even fewer resided there on a long term permanent basis.

None of the patients living at home were allowed to live alone. This is due to NC Hospice regulations requiring that patients have a primary health care provider while they are on service. The amount of time the primary health care provider needs to be available to the patient is dependent on the physical condition of the patient (varying from 24 hours a day to sometimes just a few hours a day).

It was difficult for me to determine the exact economic level of the patients visited because I did not have access to this part of the patient files. For most of the patients (either rich or poor), Medicaid or Medicare Part A was the primary payee for hospice service. Additional sources of income to pay for hospice service came from personal individual insurance coverage. Up to 10 percent of the hospice patients were not covered by federal or private funding sources. NC Hospice tried to not turn away anyone who needed their hospice assistance, and the cost incurred by these patients was written off by NC Hospice. The total number of non-

paying patients varied depending on the paying patient population. Sometimes it would be lower than 10 percent but not higher.

NC Hospice which served as the research site was constantly adding new patients as other patients died. This was called by hospice staff, "patient die-off." The vast majority of the patients using hospice service were suffering from some type of cancer, especially cancer of the lung, bladder, colon, prostate, breast, pancreas, liver, or brain. Other terminal ailments suffered by hospice patients during the period of research were, AIDS (a very small minority), dementia, Alzheimer's disease, Organic Brain Syndrome (OBS), Parkinson's disease, and various heart and pulmonary diseases. Patients often were diagnosed and on hospice service with more than one disease or disorder.

While each patient had his or her personal physician, hospice has a staff physician for each of the locations. This consulting staff physician does not replace the personal physician of the patient but rather helps them manage the terminal illness, the accompanying pain, and develop, an over all plan-of-care. The primary staff physician for the research site was a female doctor

with a speciality in oncology. She had her own private practice and was on staff at the local community hospital. I only saw her once a week when she was attending the IDT meeting. I never had a chance to interview her because she arrived just before the IDT meeting began and left right after it ended. Twice when she was unable to attend a IDT meeting, a substitute physician was called in. This physician was also a female. I do not know her background or her medical speciality; however, she was the backup staff physician.

In addition to the staff physician, there were seven field nurses, six of whom were female and one who was male. As part of the office staff, there were three other nurses; one was male who was the Program Director. This director performed staff duties but also went out into the field to see patients when he was needed.

There were four home health aids who were Certified Nursing Assistants (CNAs), three white and one black, all of whom were women in their 20's. The volunteer coordinator and the chaplain were both white males. All the rest of the staff, the office workers, the social worker and the pharmacist were Caucasian and female.

Of the volunteers I observed, the vast majority were Caucasian and female. They ranged from high school and college students to housewives, and retired individuals. Most of the students volunteering were in college or nursing school studying for medical or social work vocations. Many of the women volunteers were retired nurses or teachers. I only saw one active male volunteer other than myself, and he was a retired T.V. repairman.

Hospice organization and patient care

Both the branch hospice and the corporate headquarters exerted various influences on the care of patients. Throughout the research, there was a constant struggle by corporate headquarters to maintain a financial "bottom line" and by NC Hospice staff whose emphasis was to maintain "quality patient care."

The struggle between corporate headquarters and NC Hospice, while being interesting and a topic for a study of corporate culture, was not the direction that I intend my research to take at that time. My interest is in verbal interaction between the hospice staff and their terminally ill patients. However since it is a major

topic of conversation at NC Hospice, the conflict needs to be explained.

This struggle consisted of corporate headquarters wanting to add more patients and not hiring more employees for the increased work load. NC Hospice Program Director felt that to do so would possibly sacrifice the existing high quality of patient care. The branch hospice had to maintain a financial solvency and pay for itself. They did this by maintaining a certain number of Medicare (Part A) paying patients.

At one point in my research, some of the full time field nurses were reduced from 40 hours a week to 30 hours a week. The Program Director gave the nurses a choice of having their hours reduced or having some of the nurses temporarily laid off. This was because patient "die off" far exceeded the number of patients joining hospice. The Program Director spoke about this issue at several of the staff meetings; he also solicited ideas on how to recruit new patients by gaining the confidence and favor of local doctors.

During this time period, the corporate office increased the paperwork requirements for the field nurses due to additional Medicaid rules and regulations. The

nurses resented these additional requirements because it took away time that they could actually spend with their patients, and they felt that this increase in paperwork actually degraded patient quality care. These rules, regulations and the increase in paperwork, over time, began to alienate NC Hospice from the corporate headquarters. The management of corporate headquarters were viewed by the staff of NC Hospice as administrators only interested in the money that they could make and not interested at all in the patients and the high quality of care that these patients should receive.

Specific settings

The majority of my research was spent with the field nurses visiting with patients and their families, at their place of residence. This involved traveling with the nurses in their vehicles to their assigned patients residences. Most of the patients lived at home with family or care givers while other patients lived in nursing homes. It was from this setting that I could observe the interactions of the patients, nurses, primary care giver and family members.

I observed NC Hospice through two major settings. First, I observed the overall staff interaction in the hospice office and conducted interviews there. This was not, however, where contact with patients took place. I never saw patients come into the office even for the initial intake interview. On just a few occasions, I saw a family member of the patient visit, and it was usually to get medication or to sign forms. The second major setting was often called "the field," and it included the patients' residences. The staff went out into the field to visit, care for, and interact with patients and their health care providers on a regular basis.

It was in the setting of the office suite that most staff interaction occurred. The staff office suite is located on the ground level of a modern four story building (figure 1.). Initially, this suite consisted of six offices, a combination xerox and mail room, a reception area, a large meeting room, a storeroom, a kitchenette, and a small pharmacy. At the end of my research, (with the lease of an adjoining office suite), four more offices were added on the north end.

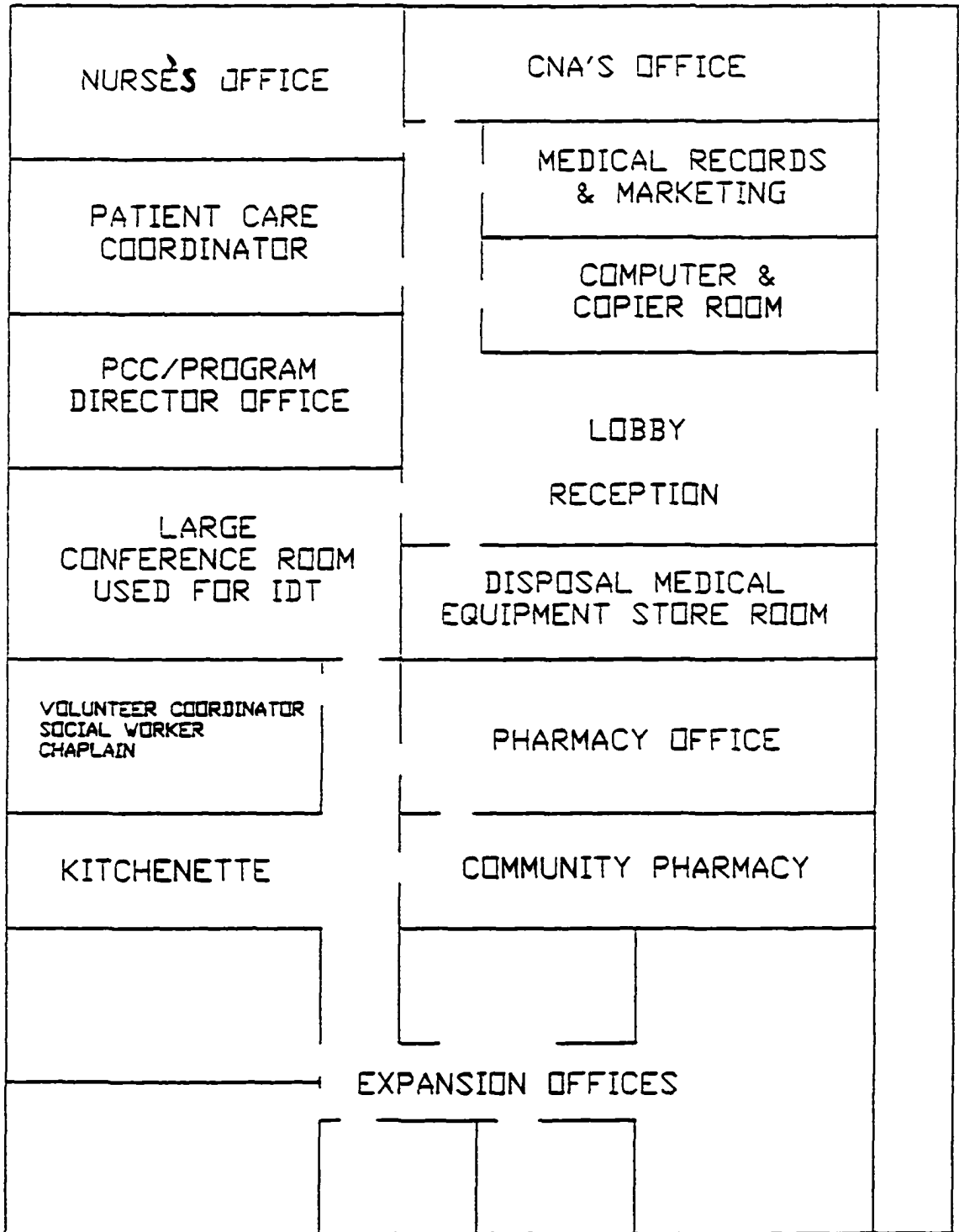
Right outside the reception area in the central hallway of the building was a water fountain, restrooms

and the main entrance to the building. Just outside the main building entrance was a public bench and a small garden. This is where hospice staff and other office personnel who smoked, gathered, and where a great deal of informal communication and socializing with other tenants of the office building occurred.

Whereas I conducted observational research throughout the entire NC Hospice office suite, most of the overall interaction and communication activities among staff members occurred in the large meeting room during the weekly IDT and staff meetings. The second primary research location was in the field nurse's office where all the nurses had desk space and where they gathered in the mornings and late afternoons.

Figure 1

HOSPICE FLOOR PLAN



The roles of hospice staff

The staff working at hospice is comprised of many different medical and non-medical specialities (figure 2.). The full time staff had additional duties of conducting initial intake interviews or "legals" for all incoming patients in addition to their primary duties. These interviews occurred at the patient's place of residence and lasted up to two hours. They were time consuming and involved a great deal paperwork. Few of the staff members enjoyed doing them, especially the nurses because they felt that it would cut into the time they could spend with their patients or increase the length of their work day.

Figure 2

ORGANIZATIONAL CHART NC HOSPICE

CORPORATE HEADQUARTERS

COMMUNITY PHARMACY NC HOSPICE

PROGRAM DIRECTOR

PATIENT CARE COORDINATOR

CHAPLIN

HOME
HEALTH AIDS

SOCIAL WORKER

NURSES

VOLUNTEER
COORDINATOR

RECEPTIONIST

MEDICAL RECORDS

Non-medical staff

One of the staff office positions was the receptionist whose job it was to answer the phones, to greet people as they came into the office and to type office correspondence.

This role was shared primarily by a designated full time employee (a female) and was often augmented with

volunteer staffing (also female). However, other office employees or even field nurses would fill in as acting receptionist when needed.

There was another woman on the office staff whose primary job was to maintain medical records. She kept the patients' medical files up to date, updated the patient board and filled out all the necessary paperwork for medicaid, medicare and hospice. As a LPN nurse, she sometimes visited patients as a substitute nurse when the staff was short handed. In emergency situations, she could also respond to death calls.

On the premises there was a small pharmacy that was owned and operated by a separate company of the hospice corporation. In operating the pharmacy this way, patient medication could be purchased in bulk and cheaper than through outside sources. The pharmacist was a female, and her primary job was to operate the pharmacy and to fill medication orders used by hospice patients.

Sharing a very small office was the volunteer coordinator, staff social worker and the staff chaplain. The volunteer coordinator was a part-time position and was taken by a male in his early 20's. His primary job

was to recruit, train, schedule and supervise the volunteers working at hospice.

The hospice social worker was a female and held a Masters of Social Work (MSW) degree which is required for the position. Her job was to help the patient and the family adapt to their new situation. In addition, she helped the family fill out the paperwork for various state and federal social services such as medicare, and medicaid. She also performed family and individual counseling and aided the family if necessary in making funeral arraignments.

The hospice chaplain was a male and an ordained minister who had completed training in CPE (Clinical Pastoral Education). A certificate in CPE and an ordination in a specific denomination is a requirement for this position. The job of the chaplain is to give spiritual support to the patient, patient's family and hospice staff members. He visits with the patients initially when they are admitted to hospice care. He returns only if requested by the patient or family. Often the family has their own spiritual advisor or does not want one.

When I asked the chaplain what he did here, he indicated the following as recorded in my field notes:

The chaplain gives spiritual support to patients while they are dying. He listens, reflects and counsels them. Although he is a Christian, he deals with other faiths also. He adapts and works through the religious differences. He helps patients and their families with their spiritual journey and tries to draw them closer to God. He tries to answer questions patients have, such as why God is doing this to me, where is God in my dying process and what is God's will in my life right now?

In addition, the chaplain completes required paperwork and sends out bereavement cards to the family when the patient dies. If the patient does not have a pastor, priest, rabbi, or other spiritual advisor, he will conduct the funeral service if requested by the patient or family. In addition, the chaplain conducts a memorial service for the hospice staff after about 25 patients have died.

The Program Director of NC Hospice is a male, a former field nurse and is responsible for the overall operation of the hospice. He does the payroll, oversees

general accounting, does initial intakes, supervises the office and nursing staff and is a liaison between his office and corporate headquarters. In addition, he is a registered nurse and continues to see patients on an as-needed basis.

The Patient Care Co-ordinator is a female Registered nurse. Her jobs is to oversee patient quality care and meet medicare and corporation policy. She conducts initial intake interviews, fills in as a field nurse when necessary and directly supervises all field nurses and the home health aids. She also sets standards for minimum nursing and CNA's visitation, establishes standards for nursing, and field nurse development as well as conducting and scheduling initial nurses and CNA initial training and their continuing education.

The home health aids are also trained CNAs (Certified Nursing Assistants). They are all females in their 20's and are responsible for non-medical care of the patient. They visit the patient sometimes daily and sometimes twice or three times weekly. Their job is to clean, wash, bath, dress, feed and otherwise take care of the patient and their general physical needs.

The field nurses are all trained registered nurses (RN) except for one who is a LPN. There were six female and one male nurse. The job of the field nurse is to generally take care of the general medical needs of the patient. They administer medications, act as a liaisons between patients and doctors, teach various medical techniques to patients and care givers, performs initial intake interviews, counsels patients and care givers on the dying process, stay with patients while they are actively dying, and take care of patients and the family immediately after death.

Hospice field Nurses Medical staff

While taking care of patients is a team effort for all hospice employees, it is the field nurses that have the most direct individual contact with the patients and their families. They develop patient care plans and have direct responsibility for the care of the patients assigned to them.

There are seven field nurses assigned directly to taking care of patients. Of these seven nurses, six are women, and one is a male. All of the nurses are trained as registered nurses (RNs) except for one LPN (Licensed

Practical Nurse). Their duties are the same as the only difference is that registered nurses can develop a formal patient care plan while the LPN cannot. This difference is mandated by the state medical board and not by skill level. However, the LPN can work under the supervision of one of the RN nurses who develops the patient care plan.

The nurse's office is in the south east corner of the office suite. Instead of individual desks there are tables set against the walls with chairs. Nurses share the same tables. Two sides of the office have windows running the entire length of the wall. There are three telephones, each with its own phone line. On the wall with the door there is a storage cabinet with various forms, pamphlets, and information used and given to patients.

The nurses work Monday through Friday beginning at about 7:30 in the morning and finish by 5:30 or 6:00 in the evening. On a rotational basis after working hours, on weekends and holidays, the nurses are, "on call nurses" answering after hours patient questions and responding when a patient dies. The "on call" nurse works one week at a time, Monday through Monday. The

hours are from 5 P.M. till 9 A.M., and there is a backup "on call" nurse incase 2 deaths occur at the same time.

After working hours, all phone calls made to hospice are forwarded to the "on call" beeper. The nurses return the phone call and either give advice over the telephone which is preferable, or they go out for a field visit. The "on call" nurse must also respond to calls when patients die. When nurses respond to a patient's death, it is called a "death call." When a death call is called into the office, the nurse must go out to where the patient lives.

On weekdays, nurses begin arriving at the office about 7 in the morning. Some arrive early to take care of paperwork from the previous day or to plan the present day. This time is also used to socialize with the office staff, to receive any new information concerning their patients and to call and make appointments with patients for that day. By about 9 o'clock, most of the nurses have left the office and have started visiting their patients. This schedule remains the same each day with the exception of Wednesdays.

Wednesdays is the day designated for the weekly IDT (Interdisciplinary Team) meeting for all staff members and is described in chapter five.

When the nurses leave to visit patients in the morning, they drive their own vehicles they are paid milage. They visit their patients at home, or in a nursing home. There is no set time spent with the patients. It just depends on what needs to be done. Sometimes the visit is scheduled around that individual patients' schedule; for example, their meals in nursing homes or any physical therapy or specific medical procedures that the patient requires.

The nurses try to do what they need to do with the patient quickly, and then move on to another patient. They balance their need to move to the next patient with spending time with the patient and their family. If they spend too long with a patient, their day just gets that much longer because they need to see all of their patients scheduled for that day. Very few patients can be rescheduled for the next day due to time constraints and the patient care plan. (The routines described in the next three pages are further specified and exemplified in chapter 5.)

Once arriving at the patients place of residence, the nurse is usually greeted by a family member or a paid health care giver. They talk about the patient's condition, special needs, medication, sleep patterns, bowel movements, and their current mental state. The nurse also asks how, the health care giver, is getting along and if they have any needs or questions. If the patient resides in a nursing home, then the nurse gets this information from the patient's medical chart and from the desk nurse if available.

When the nurse walks in to see his or her patient, he or she usually gives the appropriate greeting, "good morning" or "good afternoon" and then asks, "How are you doing today?" This is asked of all patients, even those that are known to be totally non-responsive. Nurses ask the patient general questions about how the patient is feeling, if he or she is in any pain, how he or she is eating, going to the bathroom regularly, and if he or she is sleeping well. These questions are asked while the nurse is physically examining the patient.

Nurses look at the patient's eyes, feel and squeeze their skin, check their feet, take blood pressure, check their pulse and heartbeat. They check any dressed wounds

or sores and examine other parts of their body depending on the individual needs and requirements of the patient. If necessary, they rearrange the patient in the bed or get them out of the bed and put them in a chair or move them from the chair to the bed. While they are attending to the physical needs of the patient, they also address his or her emotional and psychological needs.

The nurses talk to all patients even though many of them are in a comatose like condition, or due to their disease are unable to talk or comprehend what is going on or being said. The nurses say that these conditions are usually caused by a late stage organic brain syndrome or late stage Alzheimer's disease, dementia, or some other brain disorder. The nurses stated that although patients might seem and act unresponsive, they might not actually be unresponsive. With many of these diseases, the patient does have moments of lucidity where they can listen, understand, and respond. This is why the nurses talk to them directly and not about them in the third person context.

One of the nurses and I went to visit a patient in a nursing home who was suffering from organic brain syndrome. Before we entered his room, she told me that

he had not been responsive to her in a long time. We walked in and the nurse said, "good morning Mr. Smith (not his real name)," he responded with a strong, "good morning" and began telling her how he was feeling. He even shook my hand with a very strong grip; this was something he had been unable to do because of his deteriorating motor skills and brain functioning. When the nurse visited him the next time, he was totally unresponsive to any of the outside stimuli.

When the nurses are finished ministering to the patients and need to leave, they tell the patients when they will be back and spend some time answering their questions, comments, or listen to their fears. The nurses told me that they do more counseling with the patient than actual nursing work. On the way out, they talk to the primary care giver, answering his or her questions and comments and giving instructions to him or her about medications and any insight they have about the patient. In a nursing home, they return the patient's chart to the desk and give their comments (if they have any) to the desk nurse.

From one patient, they go to visit another. They have an hour for lunch, and by corporate policy, they

cannot work though it. If they are close to the hospice office, they return there for lunch. If they are not close to the office, then they either eat in their car or go to a favorite restaurant. After visiting patients scheduled for that day, they return to the office, try to finish their paperwork, and leave by 6:00 in the evening.

CHAPTER 5

AN ETHNOGRAPHY OF COMMUNICATION: TWO SPEECH EVENTS

In response to the descriptive ethnography of NC Hospice introduced previously, this chapter is concerned with developing an ethnography of speaking which describes a way of speaking as reflected in the sociolinguistic speech community of NC Hospice. In any social situation involving language and speaking, it is the speaker who chooses how the message will be verbalized. The speaker does this based on the social context of the verbal interaction and what is known and believed as appropriate verbal behavior for that particular social setting or sociolinguistic group (Philipsen, 1972; Goffman, 1959). In addition, this study will also look at the settings for communication, the places where communication occurs, as well as the people doing the communicating.

In this research, participant-observation is the method of research used which allowed the ethnographer to identify and explore the various communication events and their components (Hymes, 1974, 1962). This study of NC

Hospice begin as a traditional ethnographic study of a community of speakers. However, it developed into more than that. It became an ethnography of communication concerned with how a community of speakers talked to and among each other. The overall setting, in this case, is that of a community based home hospice which provides medical care for the terminally ill.

The major emphasis of this study is on verbal communication among a sociolinguistic group of language speakers. This focus on the verbal understanding of a sociolinguistic group was first defined by Dell Hymes (1962) as an ethnography of speaking. In explaining what is meant by an ethnography of speaking he states:

In one sense this area fills the gap between what is usually described in grammars, and what is usually described in ethnographies. Both use speech as evidence of other patterns; neither brings it into focus in terms of its own patterns. In another sense, this is a question of what a child internalizes about speaking, beyond rules of grammar and a dictionary, while becoming a full-fledged member of its speech community. Or, it is a question of what a foreigner must learn about a

group's verbal behavior in order to participate appropriately and effectively in its activities. The ethnography of speaking is concerned with the situations and uses, the patterns and functions, of speaking as an activity in its own right. (p. 16)

In writing an ethnography of NC Hospice, there are many activities that can be defined as speaking, but speaking as defined by the researcher, or the group being studied? The settings for verbal behavior used in this study are settings defined by the sociolinguistic group as events in which communication occurs (Hymes, 1962, p. 19). Hymes further states that:

One must reciprocally establish the modes and settings of behavior relevant to speech, and the sets of verbal items that occur with them; dimensions of contrast and rules of use, whether purely semantic (designative) or concerned with other imports and functions... The approach of course requires the structural analysis of the community in relation to speech and that would constitute an ethnography of speaking. (1962, p. 19)

According to Hymes, this structural analysis can be determined only within the boundaries of that speech community. Hymes continues:

Activity defined as speaking by one group may be defined as something else by another. But differences of this sort are themselves of interest. Some behavior will be organized and defined in terms of speaking in every group, and the import of this behavior may be missed if not investigated as such. Only a focus on speaking answers the structural question, and provides data for comparative study of the differential involvement of speaking in the structure of behavior in different groups. (1962, p. 22-23)

NC Community Hospice has many specific speech events that relate directly to communication behavior. Some examples are: the IDT meeting, the patient examination event, the intake interview, the death call, the introduction of the volunteer to his or her patient event, staff in-service training sessions, the patient's spiritual assessment by the chaplain, the patient's interview with the social worker, and the monthly memorial service.

These speech events have behavioral and sociolinguistic implications within the context in which they occur. All speech events used by this community of speakers use underlying rules of verbal conduct concerning their situation of use, patterns of use and overall function. These specific speech events do not stand alone. They are but one part of a relationship that exists between other speaking contexts and the entire speaking event. In writing about relationships between speech contexts, Hymes said:

The cognitive role of speech is not all-or-nothing, but a matter of what, where, and when. Speech is cognitively more important in some activities than others, some times more than others, for some persons more than others, for some societies more than others. (p. 19)

In this paper, the term speech event is used to mean a locally defined social context for speaking, with an internal structure that differentiates it from other events in the community and has shared rules for conduct and for the interpretation of speech (Duranti, 1988; Fetch and Philipsen, 1995; Philipsen, 1994). The instances of speech within the group can be identified

and recognized by their distinctive contextual features and by contrasting them to other speaking events (Hymes, 1962, p.24).

In describing various ethnographic techniques that can be used for the discovery of speech events, Hymes states that:

It is through the words which name them. Some classes of speech events in our culture are well known: Sunday morning sermon, inaugural address, pledge of allegiance. Other classes are suggested by colloquial expressions such as: heart-to-heart-talk, talk, bull session, chat, polite conversation, chatter (of a team), chew him out, give him the lowdown, get it off his chest, griping, etc. I know no structural analysis. Clearly the material cannot be culled from a dictionary alone: instances and classes of speech events may be labeled by quite diverse means, not only by nouns, but also by verbs, phrases, and sentences. In response to the question;, "Nice talk?," a situation may be titled by the response "Couldn't get a word in edgewise."

Insofar as participants in a society conceive their verbal interaction in terms of such

categories, the criterial attributes and the distribution of these are worth discovering. (1962. p. 24-25)

The two speech events I chose to analyze at NC Hospice are the IDT (Interdisciplinary Team Meeting) and the event I have termed the patient's bedside environment. I chose these two speech events because of their focus on conversation concerning the individual patient's dying process, and how the participants of these speech events make sense out of the talk they do, and of the situation in which that talk occurs.

The analysis that follows looks at these two distinctly separate speech events in terms of how NC Hospice employees communicate to each other about their patients, and how they use speech in a specific culturally sanctioned manner (Carbaugh, 1995; Philipsen, 1975). These situations include an analysis and description of (1) the IDT meeting and or the patient's beside, (2) an account of the social structure designated by the group as a setting for communication, and, (3) a description of the social setting used for talk.

The IDT Meeting: A Speech Event for talking about
death and dying

The IDT at NC Hospice is a meeting which consists of a group of individual health care professionals who get together on a weekly basis for the purpose of sharing information and making decisions about patient care and patient treatment. The study of group communication and the dynamics resulting from the group interaction has long been a course of study for communication scholars and researchers in other academic disciplines.

NC Hospice provides primarily palliative at home care for terminally ill patients. This service and others provided by NC Hospice are coordinated by the Interdisciplinary team (IDT). The team meets once a week to discuss each patient, to plan and coordinate palliative health care services and to disseminate information to other field staff who are involved in direct patient care.

Over the last two decades, the concept of the health care team has become a popular alternative to conventional health care throughout the medical community. The health care team is generally defined as an interdisciplinary group of care givers, doctors,

nurses, social and mental health care workers who come together and meet as a group, in order to give a specific kind of patient care (Berteotti & Seibold, 1994).

In discussing verbal social interaction, the concept of the speech event covers many different types and styles of verbal and non-verbal intercourse. The present study will focus on one type of speech event, that of an officially sanctioned regularly scheduled health-care team meeting called the IDT (Larrue & Trognon, 1993).

In further defining the speech event, Hymes states:

Taking first the speech events within a group, what are instances of speech events? What classes of speech events are recognized or can be inferred? What are the dimensions of contrast, the distinctive features, which differentiate them?...What is their pattern of occurrence, their distribution vis-a-vis each other and externally (in terms of total behavior or some selected aspect)? (1962, p. 24)

What the description of the NC Hospice IDT meeting will show is that there are speech events embedded in speech events. The IDT is a title given by NC Hospice used to identify a specific class of speech event. The IDT speech event will be studied by asking questions

about and looking at the speech event itself, like examining the components or factors of that speech event and the possible function the speech event serves within that sociolinguistic community.

Background on Interdisciplinary Team Meeting

A major weekly communicative event that occurs between employees at NC Hospice is the IDT (Interdisciplinary Team) meeting. This event happens once a week, on Wednesday mornings, and involves the participation of all the employees and volunteers who work at NC Hospice. The focus of this meeting is on medically assessing the physical, emotional and mental condition of patients currently on hospice service. One-half of the total patients on hospice service are assessed one week, and the second half on service are assessed the following week, an arrangement made primarily to keep the length of the meeting manageable.

Included in the general discussion of the patient are concerns about the family of the patient and the primary care giver. Anyone who attends the meeting may speak and contribute if he or she has knowledge of the patient or of the patient's family situation.

There are four distinct organizationally acknowledged sections to the NC Hospice, IDT meeting: opening prayer, bereavement, the medical evaluation of patients, and, announcements. The IDT follows this four section format in sequence each time the meeting is held. Following the IDT meeting and a short break, is a staff meeting, then quite often an in-service (ongoing education) training session is held for the nurses and other medical personnel.

In observing over 20 IDT meetings, this researcher noticed two additional parts to the IDT that are not formally acknowledged by NC Hospice, but are part of the meeting. They are what I call, the gathering together which occurs before the opening prayer, and the staff meeting which occurs after the IDT meeting is officially over. This meeting is separated from the IDT meeting by a short break of no more than 10 minutes.

The IDT is held in a large meeting room with central access to the rest of the office complex. There are 5 long rectangular tables in the room which are placed together to make a large square with the center filled in. This arrangement permits papers and forms to be easily moved around or across the table from person to

person. There are chairs placed around the table, but there is not enough room for all the staff to sit at the tables. There are chairs lining two of the four walls. One side of the room is used for office storage and is blocked off by a portable office divider.

Seating is not assigned, but rather is determined by job position, status and where individuals habitually or routinely sit. People who sit at the tables are the nurses and other professionally trained staff. These people are responsible for developing and implementing the weekly patient health care plan.

There are three chairs at the table that are unofficially reserved. One chair is for the staff doctor and is located by the main entrance to the room. There is an unspoken understanding that this reserved seat is to be left open because it provides easy access for the doctor as she is frequently late to the meeting and often leaves before the meeting is over.

The NC Hospice Director sits at the table next to his office entrance and to the doctor's right. The third chair is for the PCC (Patient Care Co-ordinator) who usually sits to the left of the doctor and across the corner from the director. The rest of the chairs around

the table might seem to be available for whomever sits there, but these chairs are usually taken by individuals who have a history of sitting in certain seat locations.

Persons sitting at the table on a regular basis do paperwork during the meeting that they may pass to others to read and or to sign. Included in this group are the nurses, social worker, chaplain, Director, Patient Care Co-ordinator, the doctor and myself. If there is room, everyone sits at the table. The only people who sit along the wall are those who enter the meeting late, those who are visitors, volunteers or are the home health aids (CNAs).

The gathering together

IDT meeting begins as a social event for the office when the staff begins arriving for work in the morning. On this one day out of the week, field nurses and home health aids, known as CNAs do not hurry out of the office for their daily patient visitations. The overall pace is more relaxed, and individuals talk to each other more on a social level and for longer periods of time. There might be paperwork for the nurses to complete before the meeting, but they do it and socialize at the same time.

Adjacent and down a short hallway from the IDT meeting room is the kitchenette. This is where food is brought in by various staff members who take turns purchasing and setting-up the self-serve food. Anyone, including any guests present, can help-them selves to the food. The person who signed up to bring food that day selects and brings what he or she wants. Common choices are donuts, cookies, fruit platters, or bagels with cream cheese. It is the food choices and variety of food that provides topics for pre-IDT social conversation as-well-as an impetus used to get people into the large meeting room.

The sharing of food provides a sense of community, cooperation, a sense of belonging and sharing that is necessary in dealing with patients and other employees. This sense of community and sharing that centers around food at NC Hospice is shared with other sociolinguistic groups.

In discussing the importance of food during social events, among the Warm Springs Indians, Susan Philip wrote that the kitchen area and the food served is an important part of any of their community social events. The sharing and serving of the food to the community, by

the community maintains relationships, expresses good will and shows hospitality to any visitors (Philips, 1974, p. 97).

The IDT meeting usually begins by 8:30 in the morning. People begin leaving their office space about 8 A.M., getting themselves something to eat and drifting into the meeting room to take their seat. Quite often before the meeting, the NC Hospice Director or Patient Care Co-ordinator goes around to the different offices letting people know it is time to start the IDT, and at times, actually herds them into the meeting room, so they can begin on time.

The gathering together is an important part of the IDT because it seems to set the overall lighthearted tone of the meeting. It needs to be remembered that the business of NC Hospice is dealing with the dead and dying, their families and health care providers. This is one-on-one social interaction that is stressful, depressing at times and an extremely isolating type of work for the field nurses and other staff. The gathering section of the IDT allows informal social interaction, community building, releasing and sharing of stress, and a chance to spend time with co-workers.

From the very start of the meeting, various forms and other papers are constantly shuffled around the table for people to sign or read. This continues throughout the meeting. Each person attending the meeting is given a copy of the weekly, IDT PATIENT REVIEW SCHEDULE (See Appendix C). It lists all the patients on hospice service for that week, along with their names, case number, the date they began service, their town, the diagnosis, their doctor's name, their age and date of birth, date of their last visit by the nurse, date of the next visit by the nurse and the name of the nurse presently assigned to them. Although the schedule lists all hospice patients, only one-half are reviewed each week. If all patients were reviewed each week, the meeting would last twice as long and nursing rounds for the day would not be completed.

Opening Prayer

The IDT meeting usually begins with an opening prayer being said. The prayers varied in length and content depending on who said them. Usually the individual praying was the NC Hospice Chaplain who was an ordained minister trained to be the hospice chaplain.

His prayers tended to be very ecumenical, formal and specific. The prayers of others who prayed in his absence, lay persons, tended to be very personal, unfocused and emotionally expressive.

Once most participants are seated around the table, the Director signals for the meeting to begin with a prayer by saying, "let's begin with bereavement." The prayer is usually led by the chaplain. If he is not there, the director chooses someone else. When the prayer is being said, people get quiet and bow their heads. When the chaplain prays, the words used in the prayers tend to be to-the-point, ecumenical and non-denominational in their wording and phrasing. During the data gathering phase, I did not write field notes of the prayers verbatim because the sound of my note taking was too loud. In addition; I did not record them either. Instead, I wrote down key words and phrases. Throughout the prayer, the chaplain uses words and phrases such as:

thank you, lift up, let Mr. E be safe with you;
empower us to reach out for you; think of, time and energy to reach out to help others; come together, strength and wisdom and service, extend your comfort, blessing, presence, serve your people.

In those weeks when patients died, the words, terminology and phrases of the chaplain's prayers reflected this fact. Some examples are as follows:

We will be remembering the family of --; we lift up the families, and you comfort them; remember Mr. W in the prayer; lift up Mr. A, serve him and help us reach out in his name. Let Mr. L be safe with you; let us have strength to serve in your name; empower us to reach out for you, remembering those who live, peace and comfort, use us as we minister to others in your care Jesus.

In the content of the prayers, he prays about the suffering of patients, their need for strength and the importance of the work being done by the hospice staff. In one prayer he said, "We have four persons to remember in bereavement today," and then he talked about the staff, how they were surrounded with death and how they related to their patients.

The chaplain's prayers are short and to the point; they addressed the needs of the patient, the family, their suffering and the role of hospice staff in treating the patient. This is contrasted by the content of prayers when they are said by others: When the chaplain cannot

attend the IDT and when another leads prayer (a layperson and usually a particular home health aid), the prayers tend to be very long and unfocused.

After the chaplain finished praying, he announced the time and date of the next memorial service. If there were any statements or comments made by the chaplain about individual patients, he made them after the prayer but before the social worker began her discussion of bereavement. Then, he would begin passing bereavement cards around the table for everyone in attendance to sign. These cards are sent to the families of all the patients who died that week.

Bereavement

After the chaplain finished speaking, the social worker began talking about patients that died in the past week. If the social worker was unable to attend the IDT meeting, the chaplain would take over this section. To begin this section, the doctor or the person leading the IDT said the words, "Bereavement" or "let's begin with bereavement." The personal name of the social worker responsible for doing bereavement was almost never used as a preface in announcing this section.

At this time, the social worker began her discussion of bereavement by announcing the names of those who died that week, and began giving information about them from a form titled, BEREAVEMENT ASSESSMENT AND PLAN OF CARE (See Appendix E). She read the questions verbatim from the Risk Assessment section of the form followed by the answer. The answer to each question was verbally stated as either "yes" or "no" and was usually followed by a detailed explanation. The questions on the form ask:

Is bereaved free of other family responsibility?

Is there adequate financial provision for bereaved?

Was the family able to share feelings?

Is this the only current life crisis?

Is there an adequate support system?

Is the bereaved believed to be free of suicidal ideation?

Is the bereaved believed to be free of problems with substance use/abuse?

These questions reflect specific needs and concerns hospice has about terminally ill patients and their families. The verbal reading and answering of the questions at the meeting I believe is for an information

exchange among the various disciplines seated around the table. Through dealing with the situation, these questions are aimed at ensuring that the dying person and their family have a better quality of life for the time they have remaining.

In many situations, the nurses, CNA's or other staff may have pertinent insight and answers to these questions which the social worker was unable to obtain. Additionally, these questions reflect real situations with patients and can be dealt with by various hospice staff and the resources available to them. Individuals may be dying and still have children to raise, grandparents to care for or have to work full time to provide family income. They may not have life or burial insurance, or anyone to talk to because their friends and families do not know what to say to them.

Terminally ill patients, especially those suffering from a painful cancer or other disease, often consider suicide or become abusers of the powerful pain medications that are prescribed to them. In some cases, the medication is taken from the patient by a member of the family who sells it or uses it themselves.

Once the questions were read and answered by the social worker, or by the chaplain, the nurse assigned to the patient or other staff would give additional information. These questions often generated a lot of response from the staff members who had contact with the patient, health care giver, or the family. The following segment from my field notes is an example of the social worker's response to the bereavement questions. The social worker said:

Mrs. S died at 3:15 on Tuesday. The Chaplain interjected that he sent a lot of bereavement cards, because she has a lot of family. The primary bereaved is the mother who knows almost nothing about Mrs. S's children. Does the family seem accepting of her death? Yes. Is the mother free of suicide? Yes. Is there adequate finances for the mother? Yes. Was there an expression of feelings by family members? One nurse said yes. Does the bereaved have any other current life crisis, or conflicts? Someone replied, "some family conflicts, one child is considered the "Black Sheep" and overall the kids are devastated. Is support available? Yes. Is the bereaved free of suicide?

Yes, the mom is free of drug abuse, now. Mrs. S's mother was a drug abuser. The PCC says, one of the nurses needs to pick up Mrs. S's remaining medication. There was a delivery of pain Eds (pain medication) a day before her death.

Once the bereavement questions were read out loud and answered by social services, the other members of the IDT could add what they know about the situation and come to some kind of conclusion to help the patient and family.

In another case the social worker explained: Mrs. M is free of other responsibility but not of the kids that are with D.S. (Department of Human Services). Mr. M died and his wife and the family have issues of anger. (I noted to myself that the participants were talking over the social worker while she talked and the noise built up quickly. The PCC whistled long and loud by placing her fingers between her lips and got the meeting back to order. Participants still talked over the social worker, but quieted down some what.) The finances of the family are unsure. Did the family share feelings? Yes. Is this the only current family

crisis? No. Is there adequate financial support? No. Is the bereaved free of suicide? Good question. A general discussion on the statement of suicide follows among the staff members.

The staff member who dealt with the patient gave information and other statements concerning the family that the social worker did not have. If the answers to the questions concerning the patients were no, and if there was no one around the table who had anything to add, then the social worker went through the list until she is finished. Sometimes the questions and answers were read almost in a staccato-like manner.

The exchange of information on the patient is very informal while the reading of the questions is very formal. All the questions are read in their entirety for each and every patient who died that week. Some examples of general comments made by the staff about some of the patients and their families are: "she died too soon" or "I didn't get a chance to meet the patient before she died." or "the wife buried her third husband." When the social worker finishes talking about the last patient, she usually ends by saying, "that is all for bereavement," and her section is over.

The patient's medical assessment: The IDT

When the bereavement section is finished. The IDT section of the meeting containing the medical discussion and evaluation of the patient begins. The staff doctor usually leads this section. If the doctor is going to be late, she usually calls ahead, and the IDT section is delayed until she arrives. If the doctor is going to be very late, the Director or the PCC takes over and runs the rest of the meeting until the doctor arrives. There is a second staff doctor, Dr. W, also a women, who is called when the primary doctor, Dr. L, is on vacation or cannot attend the meeting.

The IDT begins with the doctor asking about any new patients that have been brought on hospice service. The names are usually listed on the IDT sheet that is passed out ahead of time with the term "initial" written in one of the columns. These patients are discussed and assessed medically. The majority of the evaluation is done by the individual who did the "legals" (the intake interview) on the patient. This is followed by the medical assessment performed by the assigned nurse if one has been assigned. These discussions are a combination of medical diagnosis and assessment as well as an

evaluation of the social setting and the emotional state of the patient and family.

The nurse assigned to the patient gives the evaluation. If he or she is not present, the nurse reading the evaluation will give the assigned nurse's name after the patient's name is stated. One example taken from my field notes describes a typical initial intake report on a patient being admitted to hospice care.

Mr. K is the patient and has colon cancer. Teri did the initial. Other nurses laugh because the wrong patient is being talked about. He lives at home and is in pain. He lives with his blind wife who is forgetful. Mr. K. uses a wheel chair and walker. His pain is controlled with medication. His wife is kind of "demanding in a nice sort of way" Teri said. We will work hard to support them. Someone at the table said, "so help is available, but his wife is reluctant to accept it." PCC says, "we need to watch her and help her to accept and help manage his pain." The medication being used for controlling his pain is M.S. Contin, and his wife tends not to give him his pain Eds regularly.

In talking about the pain of the patient and how much pain he is actually in, the doctor says to the staff, "don't forget the patient knows how much pain he is in" we can only guess. There follows a discussion among the staff of the patient's pain medication and its adjustment to his changing physiological needs.

If anyone else had contact with the new patient or with the family they would say what they know at this time. In not every case, but in most cases, the person adding additional information is the woman who keeps the medical records. She is often in contact with the patient, their family and their doctor, usually over the telephone when getting information for her medical records and bookkeeping.

After discussing any recently admitted patients, the topic of conversation goes right to the evaluation and assessment of existing hospice patients scheduled for review that day. The doctor, or whoever is leading the meeting, reads out loud the name of the patient. The nurse assigned to that patient answers either with a detailed medical description or by saying, "responding adequately." Then, the staff would move on to the next

name on the patient list. According to one of the nurses, the phrase "responding adequately," means, "no change in the patient's condition and that they are doing fine for what they have."

Four months into my research, it was announced at the IDT by the PCC that, the phrase "responding adequately" should no longer be used as a statement of the patient's current condition. The PCC relayed that corporate headquarters felt that the use of this phrase did not give enough detailed evaluative information concerning the condition of the patient for a proper medical assessment during IDT meetings. Instead, the PCC instructed the nurses to repeat or read what they had written in the comment section of the IDT Plan of Care form that they fill out prior to the meeting for each of their patients.

When writing the evaluation of a patient, prior to the IDT meeting, either that morning or when the visit with the patient is concluded, the nurses use a specific form called Interdisciplinary Team Plan of Care (See Appendix D) as a guideline and as notes for the IDT.

The IDT Plan of Care form is another way of providing information about the patient's physical

condition. It is formal in that the form becomes a permanent written record of the patient's present condition and evaluation. This form also serves as the basis of informal verbal interaction and discussion among the staff members present at the meeting. It is through the use of this form that patient information is given to the staff which allows for discussion and evaluation input by all persons attending the meeting.

The IDT Plan of Care written form becomes a framework for speaking during the meeting. In this particular instance of speaking, the IDT form provides both the message and the channel for any verbal interaction between the senders and receivers (Hymes, 1962). Verbal interaction among hospice staff during the IDT segment of the meeting uses two channels of communication. One is the written channel provided by the IDT form. It is through the use of the written channel that the verbal channel becomes the primary channel of information exchange. According to Salzmann:

Although the acoustic channel, best exemplified by spoken words, is the one most commonly employed, other channels of communication should not be overlooked. To do so would be to ignore that

communicative behavior that makes primary use of one channel frequently depends on other channels for reinforcement. (1993, p. 198)

A parent reading a bed time story out loud to a young child uses an acoustic channel for someone who has not learned to use a written one. The verbal message is related to the written message contained in the form itself. The message of the form contains specific solicited medical information about the patient. This information is then relayed to hospice staff verbally at the IDT meeting. There is a relationship between message form and content. As Hymes, (1972, P. 59) states, "It is a truism...that how something is said is part of what is said" (as cited in Salzmann, 1993, p.199). Salzmann further explains this relationship as saying:

A paraphrase may be sufficient to indicate the message content, but only the quoting of the exact words can represent adequately the message form of a speech act. To paraphrase the statement "Like hell I'm kidding; I've warned you--now get out, fast!" as "I told him in no uncertain terms that he was no longer welcome" does away with so much color and

feeling that the changed form no longer has much in common with the original content (1993, p. 199). This relationship, as stated by Salzmann, between the message form and message content needs to be adequately shown by comparing the written IDT form to that of the IDT meeting verbal discussion.

There are 18 sections to the IDT form. Sections appropriate to the medical care and treatment of the patient are checked. The last section of the form, titled "Comments," has space for written notes. Changes in patient medication or treatment are recorded here. However, during the IDT, this form is used only as a guide and a starting point for discussing and assessing the patient. All parts of the form are not read and/or answered. The individual sections are written prior to the meeting, but the verbal interaction with other staff comes from the last section marked comments. The discussion from the comments section varies according to the patient, the patient's condition and the patient's needs.

After the last patient is discussed, specific patient and family needs, situations and comments are brought up by the staff. Then someone, usually the

doctor, the Director or the PCC says something like, "does anyone else have someone that needs to be assessed, or, is there anyone or anything, anyone would want to talk about," or if the doctor is leaving the meeting, she says, "is there anything else before I leave." If there is nothing else to add, the doctor gets up and leaves the meeting.

Announcements and the ending of the IDT

After the doctor leaves, the major portion of the meeting that addressing specific patient concerns ends. As the doctor leaves, there is usually some conversation between her and the Director and the PCC. This lasts for no more than 5 minutes. At this point in the meeting, there is no formal leadership for the meeting and the people attending the meeting routinely begin talking among themselves socially or about specific patients and issues brought up during the IDT. No one gets up or leaves the meeting area at this time.

After the doctor has left and the Director and PCC return to the meeting, they ask if there are any additional comments concerning patients assessed during the meeting. Following this discussion, the Director or

PCC asks the nurses if they have any questions or comments concerning patients not scheduled to be discussed. If they do, the meeting continues for a few more minutes. When all formal and informal conversation concerning patient assessment is finished, general announcements are made by the Director or the PCC. This includes birthday greetings, employment notices, the time of the next weekly staff meeting (usually following the IDT), the time and topic of the in-service training or the time and date of a memorial service.

Announcements are usually followed by a 10 minute break before the next section begins. If there are no other meetings scheduled, the nurses and home health aids drift out of the meeting room to their offices in small groups and begin planning their appointments for the day.

Staff Meeting

The staff meeting is a different type of speech event than other sections of the IDT meeting. The focus of verbal communication up to this point was on information exchange concerning the medical evaluation and assessment of patients. The first part of the staff

meeting deals primarily with, company policy, and office procedures.

The second part of the staff meeting, when it occurs, becomes a forum for all employees of NC Hospice to talk about what is bothering them. This forum for corporate self-disclosure is intended to help individual employees deal with the stress that accompanies working with terminally ill patients and their families on a daily basis. These sessions usually occur when there is a shortage of field nurses or when there have been a high number of deaths within a two or three week time frame. In this section, the style of the speech event changes from information gathering to that of a group therapy session.

There is a very high turnover rate of nurses who work at NC Hospice. The Director of NC hospice told me that this is due mostly to emotional burnout caused by the nurse becoming emotionally attached to the patient. When he feels the stress level is getting too high, he tries to lower it. Some of the ways he tries to accomplish this is by having an office party or another type of social event. He also has, as part of the Staff, meeting what he calls, "a bitch session" and allows the

nurses and other staff to talk about whatever they want. This results in emotional responses from whoever needs it.

When there is a staff meeting planned, it takes place after the IDT meeting is over. The staff meeting usually consists of the Director or the PCC talking to the employees about changes in procedure, protocol, paperwork, and employment opportunities. After this, the meeting occasionally becomes an event in which employees can tell how they are feeling and what is bothering them. This occurred twice while I was there. The speaking style in the next two examples shows the changes that occur in verbal styles from that of the objective information gathering of the IDT, to that of the emotional filled therapeutic self-disclosure style of the Staff meeting.

The first time the cathartic discussion occurred in my presence, it began with the director asking the staff, "Have you anything you want to say or need to bitch about: now is the time to get this thing off of your chest." Individual staff members began talking about personal issues that resulted from their employment at hospice. This was followed by an in-service training on

professional boundaries, setting limits with family and patients, and stress indigenous to the care giving professions. This evolved into a session where staff began introspective reflection into themselves and why they work with the dying. One nurse said that she thought of death as an "noble experience, like being born."

The second time this event occurred in my presence, the entire staff was working under very stressful conditions. The patient case load was high; there was an unusually high number of deaths in a short period of time, and employees were quitting and leaving for less stressful nursing occupations. The PCC began the meeting by saying, "We need a talk therapy session, and anything is open for discussion." She began the process by publically stating her feelings about the high death rate and the shortage of nurses and Corporate Headquarters' reluctance to hire more. After her statement, various individuals seated at the meeting began talking openly about how they feel about patients and about NC Hospice in general. An excerpt from my field notes reads:

We have been strung out making decisions and venting frustrations. Someone sings, 'Nobody knows the

troubles I've seen.' This results in laughter. The stress level here is awful although the "die off" load has dropped. We escort people out of this life. Within 2 or 3 weeks of coming on hospice service, the patients go into the labor of birth (This nurse uses the metaphor birthing process, to reflect the dying process). The Director says, 'all this, high number of deaths, high case load and fewer nurses, occurs in cycles. I have been here long enough to see it, and it will happen again.' The Director continues talking to the group and says: 'There have been a lots of changes here lately. Like the increased paperwork for the nurses which results in increased stress because fewer patients visited. However, the patients are still getting quality care regardless of all of us being edgy. Maintaining high patient care is important because it shows that all of you who work here care about our patients.'

When the IDT meeting ends, the staff members leave the meeting room and return to their offices. The nurses call patients for appointments, the home health aids

leave to visit their patients, and the office workers return to their work.

Discussion of the IDT

When describing an ethnography of speaking, Hymes writes that there are three aspects of speech or series of questions that need to be asked concerning a speech community (1962, p. 24). These questions are as follows: what is a speech event? What are components or factors of the speech event? (and) What are the functions of the speech event (Hymes, 1962, p.24-32; 1974, p. 51-66)?

The speech event, as stated by Fetch and Philipsen, (1995) is, "a locally defined context for speaking...which has an internal structure which differentiates it from other events in a community" (p. 265). The IDT meeting is a major event at hospice; it is associated with speech and identified by hospice and their employees as an important occurrence in the medical and social assessment of patients. It has a definable internal structure, and it is separated from other speech events by specific rules and characteristics.

Some aspects of the internal structure are the fact that there is a specific time and date for the meeting.

The meeting can be broken up into various parts: opening prayer, bereavement, IDT assessment, and announcements. There are designated leaders: the doctor, the Hospice Director or the PCC. Certain individuals are assigned to give certain types of information, such as the social worker, chaplain, or the nurse. The message form is not limited to a specific format. It can take the form of verbal, written, formal, very informal, individual, or group communication.

The various factors of the speech events provide an insider's view of the group by showing who says what to whom, their level of importance, how it is said by its language and words, and what the topic is (Hymes, 1962, p. 25; Salzmänn, 1993, p. 198-199). The emphasis is on the various members of the staff sitting around the table talking to each other about their patient's medical assessment, treatment, and overall condition.

The function of these speech events has meaning only in terms of the sociolinguistic environment of which it is part. In this case, it is the social and linguistic environment of NC Hospice. Hymes, (1974) wrote that:

the functions served in speech must be derived directly from the purposes and needs of human

persons engaged in social action...analysis of speaking is a means to the understanding of human purposes and needs...it is an indispensable means, but only a means. (p. 65)

One possible function for the style and structure of the talk used during the Wednesday IDT meeting could be to keep human emotions out of and separate from patient health care planning. By analyzing and comparing the objective nature of the internal structure of the IDT to that of the Staff meeting at NC Hospice, one can see that these two different social contexts can be associated with different styles and ways of speaking.

Juxtaposed to the IDT meeting, the Wednesday Staff meeting, held after and separate from the IDT meeting, encourages the expression of emotion filled talk with statements like, "Do you have anything you need to bitch about" or, "We need a talk therapy session?" In this way, hospice community members can deal with the emotional and personal aspect of patient care.

The IDT serves as both a time and place for the weekly group exchange of patient information needed for health care planning and various administrative services. It has a designated structure which is followed in a

specific manner using a specific language style. IDT is an important part of NC Hospice because of the function it performs as a catalyst for sociolinguistic interaction among the NC Hospice community.

The next speech event I will look at is different than the IDT meeting because it is not as structured, the talk occurs in triads or dyads, between the patient, nurse, and primary care giver. The overall goal is not the assessment of the patient, but it is to do nursing to physically and mentally treat and interact with the patient and the care giver on an interpersonal and emotional level.

The Second Speech Event: The Patient's Bedside Environment

The second speech setting I have selected is what I call the patient's bedside environment. I use this term because most verbal communication occurring between the nurse, patient, primary care giver and family usually occurs within the proximity of the bed to which the patient is fettered (the illness of the patient is advanced preventing most patients from leaving their beds, except for short periods of time). It can also

include the bedroom, the living room, the house and anywhere else on the patient's property or place of residence. If the patient is confined to a nursing home, this phase includes the room in the nursing home, the hallway outside of the room, and the nurse's station.

Whereas, the IDT provided a communication environment that encouraged mutual exchange of information by many people concerning the patient and the family, in this setting, the information exchange is less than equal. The hospice nurse is usually the information source for the patient, the primary care giver, and the family. The nurse both seeks information from the patient and the primary care giver and gives information back to them in a synthesized and useable form. This usually is in the form of instructions and knowledge about the dying process, basic bedside medical care, and the use of various medications, especially the use of pain medication.

Patients are visited on a regular basis by hospice field nurses at their place of residence. According to one of my nurse informants:

When visiting a patient, you have to remember that NC Hospice is an intrusion into the lifestyle of the

patient, the patient's family and friends. The nurse visit is for physical reasons, for mental contact, emotional support, a disinterested party there for the family and for emotional support.

The frequency of the visitation is determined by the physical needs, condition of the patient and how close the patient is to death. If the patient is ambulatory, has a busy lifestyle and can get about on his or her own, fewer nursing visits are required. In these cases, nurse visitation is scheduled for once every week, once every two weeks or as necessary.

When the patient begins to decline physically as the disease progresses, the nursing visits increase in frequency and priority. If necessary, nurses visit the patient daily. This is especially true when the patient is actively dying (death is imminent and will probably occur within 24 hrs.). According to one of my nurse informants:

There are twice weekly visits, and there are once a week visits and then when needed. As a person gets closer to death, there is continuous care in the last stages of dying...the nurses try to be there during the active stage of death to serve the

purpose of performing a psycho-social function of support for the family, from the last day to the first day, to demystify death, and to show that this is not a terrible, horrible thing.

On an average day, a nurse may visit up to 8 patients. During the period of my research at N.C. Hospice, patients I had contact with resided either in various nursing homes in the area or in private residential dwellings. Since the nursing home and the private residence are two separate communication environments, each will be individually addressed.

The Nursing Home

It is important to remember that a nursing home is a medical institution run by medical professionals. There are well established schedules and procedures for administering and caring for patients. If a patient is living in a nursing home, that facility is considered as the primary care giver for the hospice patient.

When the hospice nurse enters this environment, it is with the knowledge that there are people working there that already know how to take care of critically ill people. The only thing that NC Hospice and the nurse

have to be concerned with is the overall well-being of the patient. Any talk that occurs in this setting between the hospice patient and the hospice nurse is a reflection of the institutional environment.

The majority of the talk between the hospice patient and the nurse occurs in the patient's room. The only people present are the patient, the nurse and the roommate, if there is one. The interaction between the nurse and the patient concerns the giving and getting of medical information and the giving of comfort to the patient. The talk that occurs between them tends to be one sided. The nurse usually does most of the talking by asking questions and physically evaluating the patient.

When the hospice nurse arrives at the nursing home, the nurse usually goes straight toward the nursing station, checks in with the duty nurse and reads the patient's medical record. The medical record is read for updated information concerning patient medication and what the doctor and duty nurses say about the condition of the patient.

If the duty nurse or nursing assistant is there at the nursing station, the hospice nurse may ask him or her questions as to the current medical and physical

condition of the patient. One of my nurse informants told me that nursing home nurses, "give lots of misinformation in the charts because they are so busy." After reading the patient's chart, the hospice nurse puts it away, and then goes to visit the patient in his or her room.

Patients that are living in the nursing home usually have diseases or disorders which render them with dementia or physically unable to take care of themselves, requiring some kind of assisted care. Upon entering the patient's room, the proper greeting is said, "Good morning or Good afternoon," (name stated, either first or last) followed by or "how are you feeling today?" Nurses identify who they are by saying their name, that they are from NC Hospice and that they are the patient's hospice nurse.

Whether or not the patient can respond to the nurse verbally with the appropriate greeting, or can identify who the nurse is at all, is not important. Hospice nurses say that what is important is the saying of the greeting and that gives patients some much needed verbal stimulation. According to my nurse informant, nursing

home employees tend to be so overworked, that simple verbal stimulation of the patient is neglected.

When visiting these patients, the nurse talks continually to the patient, asking him or her questions about how he or she feels and includes him or her in the general conversation. The nurses have told me that they are observing the patient the whole time they are talking to them. One of two informants, Lynda, a female nurse, told me that when she attends to her patients, she pays attention to the little things. She uses their eyes as an assessment. "I can't put it into words what I see, but they tell me and give me information about the patient's condition." Another nurse informant, Cal, a male nurse, told me that, "When I talk to the patient, I use the conversation to observe the patient and her condition physically and emotionally." He says that he uses talk as a diagnostic tool to let him know what is going on with the patient.

Nurses use a variety of cues to identify pain and its location. If a patient cannot verbally respond to questions, then cues such as rubbing the area of pain, squirming in a chair or bed and grumpiness in demeanor can indicate pain and its possible location. Blood

pressure above the norm for that patient is another indication of pain.

When initially approaching the patient, the nurse constantly talks to the patient, asking permission to touch the patient and informing the patient of what examination the nurse is going to do to the patient before he or she does it. When the nurse actually begins to physically examine the patient, permission is asked again as if informing the patient step by step of the examination process. During one visit to a patient that I observed, the hospice nurse began talking to the patient slowly and calmly, saying the patient's name as he extended her arm to position the blood pressure cuff...He then began to explain to the patient what he was doing and asked permission each time he took her blood pressure and listened to her lungs. The conventions (rules for speaking) that nurses employ in speaking with patients with severe dementia (or similar disorder) are informed by their training and experience that while a patient may seem to be in a world of his or her own, the nurse does not actually know the level of awareness the patient has and, therefore, should avoid talking about patients in front of them. In the nurses

view, demented patients may become self aware at any moment. Therefore, when the nurse talks to the patient, it is with the assumption that the patient understands everything that is being said.

The following text is an example from my field notes of this form of dyadic interaction between a nurse and a patient with dementia. This patient has intermittent moments of conscious lucidness:

Cal and I enter the nursing home to visit Mary, and we go first to read her medical record at the nurses station, center carcusal. He read that she didn't have a bowel movement in 4 days. We go to her room, and Cal says, "Hello Mary." She opens and closes her eyes and is sitting up dragging her hand across her blanket over her chest. Her mouth is open. Cal says, "Do you remember Karl, Mary? What do you have to say for yourself today... hummmmm?" Cal stands by her bed, fills out paperwork, takes her pulse on her wrist, looks at her feet and checks for a pulse at her feet. This checks for arterial circulation, venous circulation and edema swelling in her feet, Cal tells me. He checks her mouth by first asking her to open her mouth. He then asks

her, "How does your tummy feel? Are you hurting anywhere? No! I need to check on the tube in you... (she has a feeding tube placed in her stomach) Is your tummy hurting anywhere?" (he probes and pushes on it). He uses his stethoscope to check her heart, lungs and stomach. "Let me roll your sleeve up... I want to see if you have any bruises on your arm" (rolls up sleeve) looks and studies Mary as she opens her mouth and moves her nightgown open at the bodice with her fingers and hand. Cal asks her, "Are you O. K.?" He watches her, and then says, "I'm going to take your blood pressure" (Mary is moving both hands on her blanket now). Cal finishes and takes her pulse and writes it down. Calvin tells her that he is going to talk to the nursing home staff to get her feeling better. He tells her that we are leaving, says, "goodbye" and walks out of the room.

On the way out of the nursing home, Cal stops again at the nurse's station, pulls the patient's medical record, records some notes in, it and then puts it away. If a nurse is present, they may talk for a few minutes about the patient, and then he leaves the nursing home.

After leaving the nursing home, he either goes to see another patient or returns to the hospice office.

The Private Residence

When nurses visit patients at their home residence, this new environment creates different situations and contexts in which verbal communication can occur. When the nurse visits patients who are confined in a nursing home, the primary duty consists of being an advocate for that patient and making sure that the nursing home takes proper care of them. The nurse also cares for the patient's physical and mental well being as it relates to their hospice care.

This changes when the nurse visits patients living at their home residence. Most of the patients I visited who were living at home were self aware and mentally capable of talking and interacting with another. They could get out of bed, walk around, and some could even care for themselves.

In this case, the nurse is still an advocate for these patients and cares for their medical needs and emotional well being. However, now there are other individuals in the setting who interact with, and care

for, the patient along with the nurse. This creates additional interactional situations that the nurse must address.

All patients living at home and receiving hospice care are required to have a primary care giver. This primary care giver does not have to be medically trained or certified in any way. In most cases, the individual, or individuals, are members of the family (son, daughter, grandson, granddaughter, or some other relative), a close friend of the family, or someone hired for this purpose. The typical arrangement that I observed during my field investigation was that the primary care giver was the patient's spouse.

The home environment as a speech setting contrasts markedly with the nursing home. Not only does the nurse have to interact with individual patient, she or he must also interact with the primary care giver and quite often with other members of the family. This home bedside environment provides different settings in which talk occurs and provides different individuals with whom to interact.

There is a wide range of speech events dealing with death and dying which takes place in the patient's home

that can be arranged into certain classes. Some classes of speech events I have identified are teaching, listening, counseling, dying, informing and information seeking. While it is not exactly the case that classes of speech events within this range of speech events are defined exclusively by who is in attendance and what is being said, the context is an important variable that enters into the overall shape of these speech events. The relationship between the context and the speech event was looked at by Sudnow in his 1967 ethnography of death titled Passing On. When investigating the dying¹ process, Sudnow found that the social context of death and dying in a hospital setting determined how the patient was treated and talked about. Sudnow states:

The notion of "dying" appears to be a distinctly social one, for its central relevance is provided for by the fact that it establishes a way of attending a person. Physicians and nurses don't treat "dying" but diseases and symptoms and happenings, yet they seem to have a special way of

regarding and caring for persons once they come to conceive of them as "dying." (1967, p.68-69)

These classes of speech events all have a theme, setting, or event in common. The hospice nurse teaches patient and care givers about death and dying in terms of the hospice philosophy. Other classes of speech events involving the nurse are listening to the care giver and patient, counseling the care giver and family members, seeking information about the patient and the home setting, informing the primary health care giver and or family about the results of the patient's examination. The last class I call dying, where the hospice nurse has determined that the patient is actively dying² and that death will in the next few days. All of these classes of speaking events involve extensive verbal interaction with and between the nurse, patient and the primary care giver and or family.

In many cases, the hospice nurse must act in the role of a teacher. The nurse teaches the patient and care giver what happens biologically to the human body during the end-of-life process. Quite often the field nurse has to instruct the primary care giver on the use of various types of medical equipment, such as an oxygen

breather, a suction machine or the hospital bed. In addition, the nurse may also have to teach the care giver how to perform some basic medical procedures such as putting in and taking out a Foley catheter, changing dressings for a wound, and how and when to administer the various pain medications required by the patient. The nurse also listens to and counsels the care giver, the spouse and the family, when necessary.

Patients know in advance the approximate time of the nurse's visit because of the phone call made to them earlier that morning. The nurse arrives at the residence and is greeted at the door, usually by the care giver. After greetings are exchanged, such as good morning or good afternoon, the nurse asks the care giver "How is everything going?" or some other request for information. Initially, the nurse and care giver may stand in the kitchen or living room and talk about the patient or any problems the care giver might have.

When the nurse greets the patient it is with a "good morning" or "good afternoon," followed by the question, "how are you feeling today?" If the patient answers, it is usually with a statement of how they are feeling such

as, "I feel O.K.," "I feel a little weak," or "I was able to eat today."

The patient is usually in a chair sitting up or in bed laying down. If the patient requires a hospital bed, it is usually set up in the living room or the den. Because of its large size, a hospital bed often will not fit in the bedroom so it is usually set up in the living room or the den.

I went out with the male nurse, Cal, to visit a patient in his early 60's, dying of a brain tumor. When we arrived at his house, we were greeted by the paid primary care giver, (not a member of the family) Judy. She brought us straight into the living room where Mr. H was sitting in a recliner chair. He said something to us (in guttural sounds) that Cal could not make out. Cal went over to Mr. H and began examining him, and talking to him by asking, "How are you today? Do you want to change your position in the chair?" Cal spent a few minutes just looking at Mr. H, and then wrote down what he observed on the required form.

When he finished writing, he took Mr. H's blood pressure. As he did it, he told Mr. H what he is doing. He said, "How is your shoulder? I'm going to take your

blood pressure using this arm." Cal then listened to Mr. H's heart and stomach and asked, "Is there any place in there where it hurts?" Mr. H tried to talk but did not make any sense. Cal asked him, "Are you O.K.? I'm trying to figure out what you are saying and how to respond to you." Mr. H responded with a nod of the head and possibly a change in facial expressions. After the examination, we step away from Mr. H and go with Judy to the kitchen where she wanted to talk with Cal. Cal told me he uses eye contact with Mr. H, so that Mr. H can know that Cal sees him "as someone who is still interactable with."

Mr. H's brother arrived and asked Cal about Mr. H's condition. Cal told him about his brother's present condition as related here:

His condition is still terminal, because of the brain tumor. His organs are strong, the heart, the blood pressure, the stomach, is all that of a normal person, but the brain tumor is the problem, and it will kill him. When death occurs, it will be sudden. We don't know when. Last night he was alert, talked clearly and was understandable. Today this isn't so. These ups and downs make it

difficult to predict anything. But the downs are becoming more common than the up periods, and this is not a good sign.

Judy saw us to the door, and Cal and I drove back to the office for lunch. A few days after this visit, I heard before an IDT meeting that Mr. H, was taken off of hospice service that day. I asked Cal the reason, and he said,

Mr. H's brother told this family member that I said Mr. H was going to die soon. That family member didn't want to hear the truth because he was in denial of Mr. H's disease and impending death. Cal went on to say that this family member tried to get Mr. H removed from hospice once before. Cal said that he believed the family member wanted Mr. H removed from hospice service this time because he was frightened by the blunt words Cal used the day before in describing Mr. H's condition to his brother. Hospice has a stigma associated with it, that of death. In the family members' mind, hospice brings death, and if hospice isn't there, then the patient won't die regardless of the patient's physical condition. Denial or not, Cal told me,

"Mr. H will die soon, probably in the next 2 or 3 days."

Mr. H in fact died that very evening of complications arising from his brain tumor.

Teaching the patient and the family how to speak about dying and how to view it.

One of the many functions of the hospice nurse is to teach and counsel the patient and family about death and the dying process (See Appendix E & F). The hospice philosophy does not hold death as something to be denied or not spoken openly about (See Appendix G). A great deal of the teaching and counseling done by the hospice nurse is directed toward getting the patient and family to accept death and to look at death as a natural part of the living process. Many of the nurses told me that they look at death as a birthing process and consider themselves as midwives.

Counseling and teaching patients and their families about dying is as much about listening and paying attention to their behaviors as it is talking directly to them. I went with one of the nurses, Lynda, and a

student nurse assigned to her by the name of Susan. We went to visit an elderly man in his 80's, dying of melanoma cancer that has metastasized into his liver. On the way to the house of Mr. J, Lynda gave me some background on the patient. She told me that when she visits him and his wife, she does not do much medical work but works with them emotionally and psychologically. Mr. J's wife is very afraid of her husband dying and is withholding his pain medication because of it. She tells me:

Her refusal to give her husband his pain medication is a symptom of her Mrs J's denial that her husband of 65 years has terminal cancer and is in pain. The women still will not even mention the word, 'cancer.' When I told her that the cancer will move from where it is, she changed the subject immediately. I told her that the pain will increase over time, and the pain medication will be necessary to keep him comfortable. I try to get the patient to accept what they have by being able to face the reality of their disease. They will die anyway if they really accept it or not.

Lynda told me that she informed the social worker who will counsel Mrs. J and try to get her to accept her husband's disease and death.

When we arrived at the house, Mrs. J greeted us at the door and was extremely nervous and talkative. She said that Mr. J was having trouble urinating and requires assistance. Lynda went into Mr. J's bedroom and put in a Foley Catheter. Susan and I stayed in the living room, talked and listened to Mrs. J. When Lynda came out of the bedroom, she talked to Mrs. J and taught her about the biological process of dying. Lynda tells Mrs. J that, "there was a lot of stuff in it," referring to a article she gave Mrs. J titled, "As death draws near," (Appendix F). It tells and describes the physical changes the body goes through as death occurs. As Lynda talked, Mrs. J listened some, but mostly she kept interrupting Lynda and talked about Mr. J, his urination problem and her adult children.

Lynda went back into the bedroom and checked on Mr. J. When she returned, she talked to Mrs. J and showed her how to care for Mr. J with a Foley Catheter installed, as well as how to use the bed pan and the hospital bed. We said "goodbye" and left. On the way to

the car, Susan asked Lynda if Mr. J is actively dying. She responded, "He will die when he wants to; he will push it to the limit...he could last for a month. This is due to his wife and his concern for her."

In the patient-nurse interaction, listening as well as talking plays an important part in the understanding of this setting. Various styles of talk are used by Cal and Lynda in both situations to understand the needs of the patient. For the nurses, there are general rules used in speaking which enable them to diagnose and evaluate patients even if the patients are unable to verbally communicate. In these speech settings, there is more going on than the use of abstract isolated sentences and phrases. In these sociolinguistic interactions, the participants, and the rules used to govern their speaking, are illustrated as being important aspects in the nurse, patient-family relationship.

Conclusion

This chapter is an ethnography of communication and is concerned with describing communication behavior in the context of the society in which it is part. In the two situations examined, the IDT meeting and the

patient's bedside environment, different situations for verbal communication are discussed. Both these two speech settings involve verbal interaction between the speakers, the nurse and or NC Hospice staff, the patient, and the primary care giver. These verbal interactions identified as speech events, are locally defined and have structure that delineates them from other speaking events in the community (Phillipsen, 1994).

The speech event of the IDT meeting tends to be formal in its internal structure because it is guided by convention and a written format. IDT meetings in my experience are always held on the same day of the week, at the same time, and in the same place. The reason for the weekly meetings is usually the same: to provide accurate, concise exchange of medical information of a patient between various different members of the NC Hospice health care team.

The speech event of the Patient's Bedside Environment is different than that of the IDT meeting, in that it takes place at the patient's place of residence, and tends to be more informal in structure because it is guided by the ad hoc needs of the patient, primary care giver and of the situation. The purpose of the patient's

home visitation is for hands on physical patient palliative care. However, in the words of one of my nurse informants, "I do very little physical nursing when I visit patients at home. Mostly what I do is teach and counsel them." The teaching the nurses do during these home visitations are directed towards instructing the patient and the family how to speak about dying and how to view it.

CHAPTER 6

Summary and Conclusions of the Research

This empirical study into human verbal communication is intended only as an exploration into the sociolinguistic function of speech as it applies to NC Hospice. In addition, this research, a participant-observation based case study, attempts to discover linguistic phenomena that are embedded in the fabric of the social structure. It uses an interpretive approach which has a heuristic value; however, it does not seek to test or analyze hypotheses nor does it attempt to quantify its findings.

What this study does do, is to use the contextual description of ethnographic data and extract a cultural and sociolinguistic meaning. It is in this way that I took a description of everyday life at NC Hospice and showed how the talk used by its members helped in organizing their sociolinguistic environment.

The initial description or ethnography, as described in chapter 4, gives a general explanation of the social and cultural contexts particular to those members of NC

Hospice. It is this initial description of the community which provides the background necessary to further investigate how members within that community communicate with each other. This sociolinguistic description, or ethnography of speaking, is concerned with various speech situations and speech events.

The focus of this study has been to describe the contexts in which the hospice staff, the field nurses and terminally ill patients verbally interact. The particular questions asked by this research include:

1. How does verbal and nonverbal communication operate in the hospice nurse, patient, and primary care giver/family relationship?

2. How is the terminally ill patient and their dying process discussed among the various hospice staff?

3. What are some of the settings used in talking about death and dying?

Patient, nurse, and primary care giver interactions were observed during nurse visitations and were recorded either on audio tape or in a notebook. Interviews that were conducted with the social worker, chaplain, program director, patient care co-ordinator, volunteer co-

ordinator, nurses, receptionist and medical records clerk provided additional information and perspective. Of the seven field nurses, I interviewed four and traveled extensively visiting patients with three.

Conclusion

It became clear as data analysis and syntheses progressed, that death is talked about in different ways, in different settings. Not only was the setting important to communication, but so was the function of the talk. Nurses tended to talk to and about their patients differently depending on where they were, and what they wanted to achieve.

For the overall hospice staff, talk is a valued commodity because it provides information necessary for the patient to remain relatively pain free and to participate in critical decisions about his or her terminal illness. According to Philipsen, "the place of speech in communication and social life is the discovery of where and when speech is used, and for what ends it is sanctioned" (1975, p. 22).

Implications of Two Communication Events

The first setting, the IDT meeting, is designed to assess the overall needs of the patient. The verbal interaction that takes place relates directly to the care prescription that patients will receive. There are two identifiable styles of speaking used during this meeting: formal and informal. The formal speaking style takes the form of reading questions and answers concerning the patients' physical, emotional and social well being, from a standard form that has already have been filled out. The language and wording used is very precise, and it consists of medical and psycho-social terminology. The style is standardized which allows little room for misunderstanding or ambiguity which in turn means accurate medical and psycho-social assessment, thus better patient care. Responses to these questions normally came from the doctor or the nurses, social worker or the chaplain.

The informal speaking style used during the IDT takes the form of unsolicited questions, answers, comments, or suggestions. Anyone attending the meeting could participate in this informal information gathering by telling what they know about the situation.

In sum, the communication style use in the IDT is designed so that professionally trained hospice staff can interact and understand each other on the same level using the same technical and medical language. The informal style of communication enables those personnel who have knowledge about the patient to contribute what they know, using a communication style they feel comfortable with. The end concern is better patient assessment resulting in better patient care.

The second setting, the patient's bedside environment, is connected directly to the style of care given and the physical action of performing the care by the nurse. The focus of the nurse in this setting is on the patient and their verbal interaction. The style of talk they use with their patients reflects an information gathering and exchange strategy. The nurse talks to the patient seeking information from him or her about physical status, and the patient responds verbally if physically able. If the care giver is present, he or she answers questions and provides information to the nurse either when asked or volunteers it.

This setting, the patient's bedside environment can be further divided into two separate settings. The

nursing home environment, and the patient's residential home. Each of these settings have their own characteristics and often requires a different communication style when dealing with their patients.

In the nursing home, the hospice nurse uses a style of verbal communication that is primarily one sided. The nurse does the talking, and the patients seldom answer. This is because most hospice patients that reside in nursing homes have medical conditions that render them with severe dementia and unable to respond to outside stimuli. In these situations, the nurse constantly talks to the patient asking questions and informing the patient of what the nurse is doing to them as the nurse physically examines them. If the patient responds verbally at all, it is usually not understandable.

At the home residence, the style of talk used between the patient, nurse and the care giver is an interactive style. This allows for questions, answers and feedback. The nurse still questions and talks to the patient as he or she is physically examining him or her. However, the nurse must now also deal with the care giver and any family members that are in the house.

When talking to the care giver, the nurse uses various verbal styles depending on the type of information that he or she is trying to provide them or solicit from them. Quite often the primary care giver is not medically trained and may need to be taught certain medical procedures and treatments. If the care giver is the patient's spouse, or if additional members of the family are present and the assessment of the patient is not good, then the nurse might have to act as a counselor and teacher to the family.

In summary, the nurse uses different speaking styles depending on the situations faced, these situations are embedded in the context of the setting. The communication used by hospice nurses in these speech events are rule-governed: They have a pattern and are systematic in the sociolinguistic fiber of the event.

Additional Observations

There began to emerge from my research data of NC Hospice, the beginnings of a "code," or a way of behavior, used by the nurses and other hospice staff. It is a code that pertains to the individual, the

society, and to the talk used (Duranti, 1988; Philipsen, 1972, 1975, 1990; Hymes, 1962, 1974).

In the study of ethnography of speaking, there exists a relationship between communication practices and the culture in which it is practiced (Carbaugh, 1995, 1990; Philipsen, 1992). The code specifies patterns of meaning and understanding of verbal communication as it is spoken by the sociolinguistic community (Carbaugh, 1990). In looking at the relationship between language and culture, Duranti, in a 1988 article stated that "language use must be interpreted as the use of the linguistic code(s) in the conduct of social life." It is through the understanding of sociocultural code use that researchers can begin to see how a social system can be related to a way of speaking (Carbaugh, 1990; Duranti, 1993).

At NC Hospice, the code is embedded in the talk and acts as an organizing set of rules for this sociolinguistic setting (Hymes, 1974; Philipsen, 1990). New nurse employees at NC Hospice learn appropriate hospice behavior through required new employee orientation, on-the-job training and work place socialization. What these new hospice nurses learn is to

do a different style of medicine when treating terminal patients. The goal of traditional modern medicine is to cure the patient by aggressively treating the disease any way possible (Stoddard, 1991). However, the aim of hospice is to treat the symptoms of the disease by addressing the patient's pain's or discomfort in any way possible (Smith, 1985; Stoddard, 1991). This shift in the focus of patient treatment from curative to palliative care, reflects a cultural and philosophical change for the health care professional.

The field nurses I interviewed told me that they came to work for hospice, because they wanted to have more say about the medical decisions of their patients and they wanted to nurse and care for patients in a way that was not open to them in their previous employment (usually a local hospital). They also were attracted by the tenets of the hospice philosophy in caring for the caring of terminally ill patients.

This philosophy or code of behavior that is part of the hospice culture is learned by the nurses and staff, then instilled in patients, in the patient's family and the patient's primary care giver through contact by the NC Hospice staff. The foundation of this code seems to

be identified with the Philosophy of the National Hospice Organization, as stated in the first chapter of this dissertation. Some key excerpts are:

[our aim is to] provide support and care for people in the final phase of a terminal disease ...[so, that patients] can live as fully and comfortably as possible... [We cope with] dying as a normal process [providing] personalized services and caring community. (The Basics, 1985)

This philosophy provides a frame for specific language use, and gives meaning to how that language is used in the daily life of the NC Hospice community. Knowledge of the NC Hospice code is learned by most patients, their families and care givers, primarily through contact and socialization with the hospice field nurse and hospice staff. Patients and their family are initially introduced to the code at the intake interview when the following topics are discussed: a DNR (do not resuscitate order), a living will, last will and testament if they do not already have one, suggestions on making funeral arraignments and how to apply for Medicare payments to cover the cost of hospice. They are

also informed of what hospice will provide to them as services.

During field nurse visitation, the code is further taught to patients by the matter-of-fact language use and the word choice of the hospice nurse. Euphemisms for the patient's disease and for death and dying are not used when talking to the patient, care giver or family. Instead, words and phrases which directly address the patient's condition such as cancer, terminal, death is eneviable, death is a part of life, and this disease will kill, are used as appropriate by the hospice nurse when talking to the patient, their care giver and family. It is in this way that the code of NC Hospice, talking about death, uses specific language in which to manage social life.

The emphasis of the National Hospice Organization philosophical statement is on the patient and the normalization of the patient's life. This is also what my research has shown. That the nurses and staff use differing communication styles to achieve quality care for their patient and to normalize his or her life.

However, at this point in my research I do not want to state that there definitely is a code, just that there

are strong indications that there may be one. The data I have collected certainly seems to indicate strongly that there could be one emerging out of this social setting. This would certainly indicate the need for further research in this direction in the future.

Recommendations for Future Research

Death and dying is certainly not the most uplifting subject to study. Our western society is orientated toward the future, and living life to the fullest. It is not focused on dying and the end of life. While research on death and dying is not uplifting, it certainly is rewarding, extremely interesting and very necessary. Mankind has been intrigued with this subject from their beginning. If we ignore it, it will not go away.

Yet, for all the interest we have in the subject of death, there is limited research on it outside the fields of religion, philosophy, medicine, and thanatology. These fields have studied the subject from the physical, biological, religious and philosophical point of view. None have viewed it from the perspective of how individuals actually talk about death and dying. The words that are used, the physical expressions, the

contexts and situations that occur for the receiver and the sender.

This study has just begun to open the door for the understanding of this phenomenon. There are several possible directions I would recommend for future research. First, I would repeat this study for a longer period of time and with more emphasis on communication from the patient's point of view. Second, would be to study other speech events occurring in the hospice sociolinguistic environment. Third, ethnographically study an institutional hospice where patients physically go to reside and contrast it with a community hospice where home service is provided. The fourth direction would be to look at how the hospice code is learned and acculturated by newly hired nurses.

As medicine lengthens the human life span, our society loses contact with the reality of death. As it is now, more people die in nursing homes and hospitals than at home. Culturally we do not experience nor do we want to experience dying and death. In American culture we isolate ourselves from death and the dying experience. We just see the results of death, usually on television or in a funeral home.

This study on the communication of death and others like it will become more significant as the largest percentage of the population, "the baby boomer generation" becomes older and begins to experience death for themselves. The issues of death and dying are vital to all because it affects us all. I want to end this study with an excerpt from the philosopher, Seneca who was one of ancient Rome's greatest first century thinkers. He taught concerning death, that:

we must not fear death. The true philosopher is especially too dignified to be intimidated by such extinction, and philosophical contemplation will easily liberate him from similar concerns. More specifically, the best solution to this problem is to think of death constantly, stressing the fact that we are part of nature and, therefore, must accept our destiny. (Cited in Bardis, 1981, p. 34)

ENDNOTES

1. No actual names are used here or elsewhere in this document to identify individual patients, nurses or other people connected with this study.
2. Sudnow uses "dying" to refer to a social status that allows the hospital staff to act in certain ways resulting in a particular kind of treatment toward the dying patient. Refer to Sudnow's Passing On, chapter 4 for an in depth description of the ways in which the dying are treated.
3. Organization, corporations, or businesses can either identified by the State Tax Commission as having either, non-profit or for profit status.
4. Refer to endnote 3.
5. According to Stephenson (1985), "Sudnow presents us with the stark reality; dying is affected by the social context in which it occurs" (p.56).
6. As outlined in Appendix H.

BIBLIOGRAPHY

- Agar, M., H. (1986). Speaking of ethnography. Newbury Park, CA: Sage Publications.
- Anderson, P. (1992). Hospices provide the best care for the terminally ill. In D. L. Bender, B. Leone, & W. Dudley, (Eds.), Death and dying. San Diego: Greenhaven Press, Inc.
- Arntson, P. (1989). Citizen's health competencies. Health Communication, 1(1), 29-34.
- Bardis, P.D. (1981). History of thanatology: Philosophical, religious, psychological, and sociological ideas concerning death from primitive times to the present. New York: University Press of America.
- Becker, E. (1973). The denial of death. New York: The Free Press.
- Beresford, L. (1993). The hospice handbook: Complete guide. Boston, MA: Little Brown and Company.

Bertectte, C. R., & Seibold, D. R. (1994).
Coordination and role-definition problems in health-care
teams: A hospice care study, In L. R. Frey (Ed.), Group
communication in context: Studies of nature groups (pp.
107-1310). Hillsdale, NJ: Laurence Erlbaum Associates
Publishers.

Brolan, D. J. (1993). Physician-patient-family
communication over the course of chronic illness, with a
focus on cancer care. Unpublished doctoral dissertation,
Syracuse University: Syracuse, N.Y.

Burleson, B. (1984). Comforting communication. In
H. Sypher & J. Applegate (Eds.), Communication by
children and adults: Social cognitive and strategic
processes (pp. 63-104). Beverly Hills CA: Sage.

Burgoon, M., Callister, M. & Hunsaker, F. (1994).
Patients who deceive: An empirical investigation of
patient-physician communication. Journal of Language and
Social Psychology, 13, (4), 442-368.

Burleson, B. (1984). Comforting communication. In
H. Sypher & J. Applegate (Eds.), Communication by
children and adults: Social cognitive and strategic
processes (pp. 63-104) Beverly Hills CA: Sage.

Burleson, B. (1990). Comforting as everyday social support: Relational consequences of supportive behaviors. In S. Duck (Ed.), Personal relations and social support (pp. 66-82). London: Sage.

Carbaugh, D. (1989) Deep agony; "Self vs. "Society" in Donahue discourse. Research on Language and Social Interaction, 22, 179-212.

Carbaugh, D. (1990). Communication rules in Donahue discourse. In D. Carbaugh (Ed.), Cultural communication and intercultural contact (pp. 119-149). Hillsdale, NJ: Laurence Erlbaum Publications.

Carbaugh, D. (1995) The ethnographic communication theory of Philipsen and association. In D. P. Cushman & B. Kovacic (Eds.), Watershed research tradition in human communication theory (pp. 269-298); Albany, NY: SUNY Press.

Cherry, K., & Smith, D. H. (1993). Sometimes I cry: The experience of loneliness for men with AIDS. Health Communication, 5(3), 181-208.

Cline, R. J. W., Johnson, S. J., & Freeman, K. E. (1992). Talk among sexual partners about AIDS: Interpersonal communication for risk reduction or risk enhancement? Health Communication, 4, 39-56.

- De Spelder, L. A., & Strickland, A. L. (1983). The last dance: Encountering death and dying. Palo Alto, CA: Mayfield Publishing Company.
- DuBois, P. M. (1980). The hospice way of death. New York: Human Sciences Press.
- Duranti, A. (1988). Ethnography of speaking; toward a linguistic of the praxis. In F. H. Newmeyer (Ed.), Linguistics; the Cambridge survey (Volume IV) (pp. 210-228). Cambridge, GB: Cambridge University Press.
- Duranti, A. (1993). Intension, self, and responsibility: an essay in Samoan ethnopragmatics. In Hill, J. H. & Irvine, J. (Eds.), Responsibility and evidence in oral discourse (pp. 24-47). Cambridge, GB: Cambridge University Press.
- Duranti, A. (1994). From grammar to politics: Linguistic anthropology in a western Samoan village. Los Angeles: University of California Press.

Edgar, T., Freimuth, V. S., Hammond, S. L.,
McDonald, D. A. & Fink, E. L. (1992). Strategic sexual
communication: condom use resistance and response.
Health Communication, 4(2), 83-104.

Eggerman, S., & Dustin, D. (1985-86). Death
orientation and communicating with the terminally ill.
Omega, 16(3), 255-265.

Evans, S. H., & Clarke, P. (1983). When cancer
patients fail to get well: Flaws in health communication.
In R. N. Bostrom & B. H. Westley (Eds.), Communication
Yearbook 7 (pp. 220-239). Beverly Hills: Sage
Publications.

Fitch, K. L. (1994). The issue of selection of
objects of analysis in ethnography of speaking. Research
on Language and Social Interaction, 27 (1), 51-93.

Fitch, K. L., & Philipsen, G. (1995). Ethnography
of speaking. In J. Verschueren, J. Ostman, & J.
Blommaert (Eds.), Handbook of Pragmatics, Manuel (pp.
263-269). Philadelphia: John Benjamin Publishing
Company.

Fitzpatrick, M.A., Edgar, T., & Freimuth, V.
(1992). Communication, language and health: An overview.
Journal of Language and Social Psychology, 11(1), 1-8.

Gantz, W., & Greenberg, B. S. (1990). The role of informative television programs in the battle against AIDS. Health Communication, 2, 199-215.

Garfinkel, H. (1967). Studies in ethnomethodology. Englewood Cliffs, NJ: Prentice-Hall, Inc. Publishers.

Geertz, C. (1973). The interpretation of cultures. New York: Basic Books, Inc. Publishers.

Glaser, B. G., & Strauss, A. L. (1965). Awareness of Dying. Chicago: Aldine Publishing Company.

Glenn, L. D. (1990). Health care communication between American Indian women and a white male doctor: A study of interaction at a public health care facility. Unpublished doctoral dissertation, University of Oklahoma, Norman.

Goffman, E. (1959). The presentation of self in everyday life. New York: Anchor Books.

Gotcher, M. J. (1993). The effects of family communication on psycho social adjustment of cancer patients. Journal of Applied Communication Research, 21(2), 176-188.

Gotcher, J. M. & Edwards, R. (1990). Coping strategies of cancer patients: Actual communication and imagined interactions. Human Communication, 2(4), 255-266.

Greene, K., Parrott, R., & Serovich, J. M. (1993). Privacy, HIV testing, and AIDS: College students' versus parents' perspectives. Health Communication, 4, 59-74.

Gubrium, J. F. (1975). Living and dying
murphy manor. New York: St. Martin Press.

Hammond, S. L., Freimuth, V. S., & Morrison, W. (1990). Radio and teens: Convincing gatekeepers to air health messages. Health Communication, 2(2), 59-67.

Hansen, J. C., & Frantz, T. T. (Eds.). (1984). Death and grief in the family. Rockville, MD: Aspen Publications.

Harwood, J. (1995). Intergroup self-stigmatization: Talk about stigmatized elements of the ingroup in the communication of the elderly and the dying. Paper presented at the meeting of the Speech Communication Association, San Antonio, TX.

Hastings, J. B. (1993). A trajectory model of social movement development: The case of hospice in America. Unpublished doctoral dissertation, Brown University.

Hensyl, W.R. (Ed.). (1990). Steman's medical dictionary 25th edition. Baltimore: Williams & Wilkins.

Heritage, J. (1984). Garfinkel and ethnomethodology. Cambridge: Polity Press.

Hines, S., Babrow, A.S., Badzek, L., & Moss, A. (1996). Communication and problematic integration in end-of-life decisions: Dialysis decision among the elderly. Paper presented at the meeting of the Speech Communication Association, San Diego, CA.

Hines, S., Moss, A., & McKenzie, J. (1995). Prolonging life or prolonging death: Communication's role in difficult dialysis decision. Paper presented at the meeting of the Speech Communication Association, San Antonio, TX.

Hinton, J. (1980). Sharing or withholding awareness of dying between husband and wife. Journal of Psychometric Research, 25(4), 337-343.

Hospice fact sheet. (1996, July). Pamphlet of the National Hospice Organization. Arlington, Va.

Husserl, E. (1960). Cartesian Meditations. The Hague: Martinus Nyhoff.

Hymes, D. H. (1962). The ethnography of speaking. In T. Gladwin & W. C. Sturtevant (Eds.), Anthropology and human behavior (pp. 13-53). Washington, DC: The Anthropological Society of Washington.

Hymes, D. H. (1974). Foundations in sociolinguistics: An ethnographic approach. Philadelphia: University of Pennsylvania Press.

Kastenbaum, R. J. (1981). Death, society, and human experience. St. Louis, MO: The C.V. Mosby Company.

Kastenbaum, R. J. (Ed.). (1979). Between life and death. New York: Springer Publishing Company.

Kalish, R. A. (1979). Contacting the dead: Does group identification matter. In, R. J. Kastenbaum (Ed.), Between life and death (pp. 60-64). New York: Springer Publishing Company.

Korsch, b. M. (1989). Current issues in communication research. Health Communication, 1(1), 5-9.

Kreps, G. L. (1993). Communicating about death. In B. C. Thornton & G. L. Kreps (Eds.), Perspectives on health communication. Prospect Heights IL: Waveland Press.

Kreps, G. L. (1988). The pervasive role of information in health and health care: Implications for health communication policy. In J. A. Anderson (Ed.), Communication yearbook 11 (pp. 58-88). Newbury Park, NJ: Sage Publication

Kreps, G. L., & Thornton, B. C. (1992). Health Communication: Theory and practice. Prospect Heights, IL: Waveland Press Inc.

Kubler-Ross, E. (1978). To live until we say good-bye. Englewood Cliffs, NJ: Prentice Hall, Inc.

Kubler-Ross, E. (Ed.). (1975). Death: The final stage of growth. Angled Cliffs, NJ: Prentice Hall, Inc.

Larrue, J. H. & Trognon, A., (1993). Organization of turn-taking mechanisms for turn-taking repairs in a chaired meeting. Journal of Pragmatics, 19, 177-196.

Lefevre, C. J. (1992). Communicative needs of the terminally ill elderly and the role of the hospice volunteer. Unpublished doctoral dissertation, University of Oregon.

Leiter, K. (1980). Primer on ethnomethodology. New York: Oxford University Press.

Leman-Stefanovic, I. (1987). The event of death: An phenomenological enquiry. Dorderecht, The Netherlands: Martinus Nijhoff Publishers.

Ling, J. C. S. (1989). New communicable diseases: A communication challenge. Health Communication, 1, 253-260.

Littlejohn, S. W. (1989). Theories of human communication. Belmont CA: Wadsworth Publishing Company.

Lukeman, B. (1982). Embarkation: A guide to dealing with death and parting. Angled Cliffs, NJ: Prentice Hall.

Margolis, J. (Ed.). (1968). An introduction to philosophical inquiry. New York: Alfred A. Knoph.

Miller, V. D. & Knapp, M. L. (1986). The post nuntio dilemma: Approaches to communicating with the dying. In M. L. McLaughlin (Ed.), Communication Yearbook, 9 (pp. 723-738). Beverly Hill, CA: Sage Publishing.

Munley, Anne (1983). The hospice alternative: A new context for death and dying. New York: Basic Books.

Narasi, B. H. (1992). Hospice Humor and Watson. Unpublished master's theses, D'Youville College, Buffalo, NY.

National Hospice Organization. (1985). About hospice. South Deerfield MA: Channing L. Bete Company Inc.

Nimocks, M. J. A., Webb, L. & Connell, J. R. (1987). Communication and the terminally ill: A theoretical model. Death Studies 11, 323-344.

Nuland, S. B. (1994). How we die: Reflections on life's final chapter. New York: Alfred A. Knoph Inc.

Nussbaum, J. F. (1989). Directions for research within health communication. Health Communication, 1 (1), 35-40.

Perloff, R. M., & Ray, G. B. (1991). An analysis of AIDS brochures directed at intravenous drug users. Health communication, 3(2), 113-125.

Phillips, S. U. (1974). Warm springs "Indian time": How the regulation of participation affects the progression of events. In Bauman, R. & Sherzer, H. (Eds.), Explorations in the ethnography of speaking (pp. 92-110). London: Cambridge University Press.

Philipsen, G. F. (1972). Communication in teamsterville: a sociolinguistic study of speech behavior in an urban neighborhood (Doctoral dissertation, Northwestern University, 1972). University Microfilm: Ann Arbor.

Philipsen, G. F. (1975) Speaking "like a man" in teamsterville: culture patterns of role enactment in an urban neighborhood. Quarterly Journal of Speech, 61, 13-22.

Philipsen, G. F. (1990) Reflections on speaking "like a man" in teamsterville. In D. Carbaugh (Ed.), Cultural Communication and Intercultural Contact (pp.21-26). London: Laurence Erlbaum Associates Publishers.

Philipsen, G. F. (1992). Speaking culturally: Explorations in social communication. Albany, NY: SUNY Press.

Reardon, K. K. (1990). Meeting the communication/persuasion challenge of AIDS in workplaces, neighborhoods, and schools: A comment on AIDS and public policy. Health Communication, 2(4), 267-270.

Salzmann, Z. (1993) The ethnography of communication. In Z. Salzmann (Ed.), Language, culture and society: An introduction to linguistic anthropology (pp. 193-211). Boulder, CO: Westview Press.

Sharrock, W., & Anderson, B. (1986). The ethnomethodologists. London: Tavistock Publication.

Shute, N. (1997, February 24). Death with more dignity. U. S. News & World Report, 61-62.

Schultz, A. (1962). Collected Papers I. The Hague: Martinus Nijhoff.

Sharrock, W., & Andersen, B. (1986). The ethnomethodologists. London: Tavistock Publication.

Shute, N. (1997, February 24). Death with more dignity. U. S. News & World Report, 61-24.

Siebold, C. (1992). The hospice movement: easing death's pain. New York: Twayne Publishers.

Smith, W. J. (1985). Dying in the human life cycle: physiological, biomedical, and social perspectives. New York: Holt, Rinehart and Winston.

Stephenson, J. S. (1985). Death, grief, and mourning: Individual and social realities. London: The Free Press.

Stoddard, S. (1991). The hospice movement: A better way of caring for the dying. New York: Vantage Books.

Sudnow, D. (1967). Passing on: The social organization of dying. Angled Cliffs, NJ: Prentice Hall, Inc.

Sullivan, C. F. & Reardon, K. K. (1986). Social support satisfaction and health locus of control: Discriminators of breast cancer patients styles of coping. In M. L. McLaughlin (Ed.), Communication Yearbook 9 (pp. 707-721). Beverly Hills CA: Sage Publications.

The basics of hospice. (1985). Pamphlet of the National Hospice Organization. South Deerfield, MA: Channing L. Bete Co.

Thompson, T. L. (1989). Communication and the dying: The end of the life-span. In J. F. Nussbaum (Ed.), Life-Span Communication: Normative Processes (pp. 339-359). Hillsdale, NJ: Lawrence Erlbaum Associates Publisher.

Thornton, B. C., & Krebs, G. L. (1993). Perspectives on health communication. Prospect Heights, IL: Waveland Press, Inc.

Wass, H. (1979). Dying: Facing the facts. Washington, D.C.: Hemisphere Publishing Co.

Webster's seventh new colligate dictionary. (1969). Springfield, MA: G. & C. Merriam Company.

Wieder, L. D. (1989). Language and social reality: The case of telling the convict code. Washington, DC: Center for Advanced Research in Phenomenology and University Press of America.

Wortman, C. B., & Dunkel-Schetter, C. (1979). Interpersonal relationships and cancer: A theoretical analysis. Journal of Social Issues, 35(1), 120-205.

Zimmermann, S. (1994). Social cognition and evaluations of health care team communication effectiveness. Western Journal of Communication, 58, 116-141.

Zimmermann, S. & Applegate, J. L. (1992). Person-centered comforting in the hospice interdisciplinary team. Communication Research, 19(2), 240-263.

Zook, E. G. (1994). Embodied health and constitutive communication: Toward an authentic conceptualization of health communication. In S. A. Deetz (Ed.), Communication yearbook 17. Thousand Oaks, CA: Sage Publications.

Zook, E. G. (1993). Diagnosis HIV/AIDS: Care giver communication in the crisis of terminal illness. In E. B. Ray (Ed.), Case Studies in Health Communication (pp. 113-128). Hillsdale NJ: Laurence Erlbaum Publishers.

APPENDIX A

Hospice Philosophy⁶

Hospice is a special ministry of care and love which affirms the closing of one's life with dignity and integrity. In the face of terminal illness, when there is nothing more that can be done to cure the disease, there is still much that can and needs to be done for the patient and family according to the hospice philosophy. Hospice is a specialized health care program emphasizing the management of pain and other symptoms associated the terminal illness and providing care for the family as well as the patient. Hospice services are designed especially to help terminally ill patients and families face the physical, emotional, social, financial, and spiritual aspects of their lives, and the patient's death, together in an atmosphere of support and acceptance. The patient is helped to take care of unfinished business, and to bring life to a close with a sense of completion. He/she is helped to "return to life." Hospice recognizes dying as a normal process and

neither hastens nor postpones death.

Hospice care is available to all persons without regard to diagnosis, race, age, sex, religion, national origin, handicap, sexual preference, marital status or ability to pay. Through the use of a highly trained team of hospice professionals the terminally ill are provided meaningful care close to their lives, and their loved ones are supported in the grief process as they adjust to their loss.

To this end, the hospice brings its love and care.

6. Copied from HC Hospice employee handbook, dated 1995.

APPENDIX B

History of Hospice

In looking at the history of hospice, we need first to look at ancient Greece around 400 B.C. A town named Epidaurus was known for its medical facilities and patient care system resembling a holistic approach to medicine (Stoddard, 1991). This was a place of healing using medical herbs, exercise, mud baths, and theater. The physicians used treatments such as hypnotherapy, behavior modification, and interpretive dream therapy. The patients being healed were the rich and powerful of the day. This facility was for the treatment of sick persons and not for the dying. Terminally ill patients were turned away (Stoddard, 1991).

The next patient care system comes from Rome around 300 B.C. The system was designed to care for three valuable population groups of the Roman Empire: soldiers (needed for conquest), gladiators used for entertainment), and slaves (expensive and needed in building the empire) (Siebold, 1992 & Stoddard, 1991). This system called valetudinaria, consisted of a group of wooded barracks set in a square with doctors and

attendants taking care of their patient. In these facilities, patients had no control over their care or treatment. They were treated and released to return to their duties as soon as possible (Stoddard, 1991).

It was religion, Christianity and later Islam, who saw the care of the infirm and dying as their sacred duty. Their motivation to treat the sick was not only for altruistic reasons, but they believed that by helping others, their own soul would be saved. In 325 A.D. at the council of Nicea, church doctrine was established to provide a hospice in every city with a cathedral.

Moslems also built hospices throughout the Islamic world. Their medical treatment was obtained from ancient Greek source documents. The Moslems, in addition to maintaining Greek medical knowledge and literature, advanced medical wisdom by introducing scientific principals of medicine to Western culture during the Renaissance period (Siebold, 1992, p.16).

It was after the fall of the Roman Empire in 395 A.D. that the Middle Ages, or Dark Ages began. Most people associate this period with cultural stagnation. In reality this was a period in which hospice flourished and spread throughout Europe. By the time the Crusades

began in the 11th century, there were an estimated 750 hospices located in cities, wilderness area, monastic hermitages, mountain passes and river crossings. They were places of welcome to weary travelers, crusaders and pilgrims on their way to religious holy shrines. These hospice facilities were open to orphans, lepers, pregnant women in labor and the sick and dying. The purpose of these hospices was to provide hospitality, protection, fellowship, and love but not necessarily to cure illness (Siebold, 1992 & Stoddard 1991).

During the 11th century, an organized system of hospices and hospitals were established by the Hospitaller Knights throughout Europe and Syria. The Order of St. John of Jerusalem established on the island of Rhodes and Malta a large hospice for the care of the sick and wounded pilgrims coming from and to the Crusades (Siebold, 1992 & Stoddard, 1991). These hospices were not only for the care of men; the Saint Mary Magdalene Hospice was established for the care of women (Siebold, 1992).

An example of the care and comfort given at hospices to travelers, the sick and dying across Europe and the

Holy Lands was characterized by Stoddard in describing the, "famous hospice-hospital" in Rhodes:

In the great hall here, 'Our Lords the Sick' were received. They were gently washed and carried to their beds, each with its own curtain around it, and there they were served by the noble knights themselves, who brought them...none but the best and most delicate of foods and drinks...The wisest of physicians visited them daily, diagnosing and prescribing for their ills...the director of the hospital himself was ordered twice each day to speak to each and every patient, giving comfort and encouragement...at the hospital at Rhodes,...' for the first time, patients with incurable diseases were separated from all others.' And where were they put? In a group of eleven small rooms clustered around the second-story balcony, which were also reserved for pilgrims and travelers...The little rooms are quiet and airy, golden-hued.

(Stoddard 1991, p. 34-35)

The medical treatment provided at hospices up through the Crusades was provided by priests, nuns and religious care givers. These care givers did what they

could, using the medical knowledge of the day. This medical knowledge was primarily based on contemporary superstition as well as religious dogma (Siebold, 1992). However well meaning these techniques were, they did little to quell the epidemics of the day. Bubonic plague, leprosy, smallpox and other diseases were sweeping Europe and the Mediterranean during the 5th through the 13th century. These epidemics killed from one-third to one-fourth of the population of Europe (Stoddard, 1991).

The church of the middle ages, in spite its their good intentions to build hospices, was actually responsible for holding back scientific progress in medicine. The teaching of the church regarding medical practices were based in the belief of helping others, doing good words and saving souls (Siebold, 1992). Its approach was more metaphysical than scientific. In fact, in 1163, a church edict was issued which, "forbade any surgery that caused blood to be shed. The body was the sacred repository of the soul, and any surgery was a desecration" (Bronowski, 1973 as cited by Siebold, 1992, p. 17).

The Renaissance period 1300-1600 A.D. was an age of renewed learning, limited scientific and rebirth of art and literature. It was also during this time 1528 that Henry VIII shut down the monasteries, confiscated their lands, property and dispersed this former church property and wealth to his political supporters. There were no provision made to care for those sick and dying individuals cared for in these monasteries and the hospices they had provided. In 1550, Henry VIII wrote a statute declaring that the poor and sick were to be whipped, beaten chained and branded (Stoddard, 1991 p.36, 75). It was during this time that the hospice of the Middle Ages began to disappear from England. The plight of the poor and dying individual changed from being seen as spiritual, redemptive and closer along their journey to God, to that of being a degenerate and a outcast of society (Siebold, 1992 & Stoddard, 1991).

It was during the Religious Reformation that medical care shifted from the dominance of the church to that of secular scientists. Scientific investigation, experimental study and discovery were encouraged and flourished. While diseases continued to remain incurable, contemporary scientists studied human

physiology, establish theories and looked at diseases in terms of physiological and pathological constructs (Siebold, 1992).

Industrialization and the Industrial Revolution played a part in the resurgence of hospital and health care for the masses. People migrating from rural areas were coming into the cities for employment at the factories. They soon became ill with typhoid, tuberculosis and other diseases associated with crowded cities and unsanitary conditions. These people were away from their families and the support these families provided for them when they were sick. Since the extended family wasn't available to take care of them, they turned to the existing hospitals for help. The purpose of these hospitals was to heal the individual and send them back to work (Siebold, 1992).

People with contagious diseases, or was dying or, orphaned were housed separately in almshouses and workhouses usually under the most miserable of conditions. These institutions were limited in number, usually overcrowded and had very limited services. Often people were just as likely to end up on their own in the street. Charles Dickens wrote about and described the

poor conditions in these places in his books, Oliver Twist and Our Mutual Friend.

During the 1800's, hospitals became places of teaching and research. Diseases were being treated from the perspective of a biomedical model using newly discovered fundamental scientific principals. Some terminally ill patients lucky enough to be sponsored by wealthy patrons interested in medical science were promised medical care and a proper burial in exchange for being the subjects for scientific research (Stoddard, 1991).

There were those individuals who for altruistic or religious reasons and in spite of societal norms, continued to treat the sick and dying. They were usually religious and members of Protestant Guilds such as the Quakers or the Catholic orders of Augustinians, Benedictines and the Franciscans. In 1600, St. Vincent de Paul a former slave and French priest established the Daughters of Charity who started hospices in Europe and America. In the 1700's, a similar movement was established in Prussia by Baron Von Stein (Stoddard, 1991).

It was Sister Mary Aikenhead a member of the Irish Sisters of Charity and co-worker of Florence Nightingale who was familiar with St. Vincent de Paul hospices in France. She revitalized the hospice concept by establishing, Our Lady's Hospice in Dublin Ireland, in 1879. It was the first religious facility designed to give palliative care for the dying poor (Siebold, 1992). Sister Mary Aikenhead's view of hospice spread and lead to the establishment of hospices in England, France, Australia, and the United States.

In 1906, the English Sisters of Charity founded St. Joseph's hospice in England. It was in this hospice in 1946 that Dr. Saunders the founder of the contemporary hospice movement first took a position as medical officer (Siebold, 1992).

Hospice in America

American in the 1600, 1700 and 1800's developed socially and medically much along the same line as Europe. There were workhouses and almshouses, and in many towns, they were usually the only medical care available. Hospice organizations were created in the late 19th century primarily for cancer patients who were

unwelcome or neglected in these workhouses or almshouses (Siebold, 1992). Early hospices were viewed negatively by the public and were commonly called, "Death Houses." These American hospices developed because contemporary hospitals were unable or unwilling to care for terminally ill patients. Like the European tradition of hospice, American hospice facilities followed the tradition of being created by groups of religious conscious individuals (Siebold, 1992).

In the late 1890's, The Dominican Sisters of Hawthorne, established by Nathaniel Hawthorne's daughter Rose Hawthorne, founded Saint Rose's Hospice in lower Manhattan. It was based on the European model of an inpatient facility for treating terminally ill patients. The Dominican Sisters of Hawthorne went on to build six other hospice's in New York, Denver, Philadelphia, and St. Paul. These facilities emphasized palliative care and spiritual comfort during the patient's remaining days of life.

The help these first American hospices provided is similar in focus to the hospice philosophy fostered over 50 years later in the 1970's. Both wanted to provide help for terminally ill cancer patients in providing an

alternative method of care. A point where the old and new hospice philosophy differed is on involvement of the family. The contemporary hospice position included the family as part of the total care package. The Dominican Sisters of Hawthorne limited family involvement and visitation because they believed that the family had suffered enough. They believed that once a patient was admitted to their hospice, the care of the patient should be given over totally to the Sisters. They would do what would be best for the patient and the family.

The modern hospice movement did not necessarily develop out of these older programs. It emerged due to inadequate care terminally ill patients were receiving in hospitals and nursing homes. Professional and lay-health care providers observed that hospitals and nursing homes were not prepared to treat dying patients. According to Wass (1979), terminally ill patients were often "transferred back and forth between the hospital and the nursing home because 'this patient doesn't belong here'". The reality was that neither institution had the time, space, or training to deal specifically with terminally ill patients.

Some medical professionals in the 50's and 60's began to speak out against the treatment and the neglect the terminally ill were receiving. Dr. Cicely Saunders in England and Dr. Kubler-Ross in the United States spoke out against the existing health care practices that dehumanized or ignored the dying person. They both wanted reform and wanted to change the way terminally illness was addressed by the medical community.

Appendix C

IDT PATIENT REVIEW SCHEDULE IDT Meeting for the week of 07/26/95-08/02/95

07/26/95

MR#	PATIENT NAME	DX & PHY	FREQ	DUE DATE	COMMENT
25076M 07/21/95 CC	OSMAN 05/24/14 (81)	Prostate CA Dr.	q2	07/26/95	
25075M 07/18/95 Norman	HELEN 02/08/23 (72)	Lung & Colon CA Dr.	q2	08/02/95	Debie
25074M 07/14/95 Lexington	DELPHIS 10/07/95 (80)	Lung CA Dr.	q2	08/02/95	Teri A.
25073M 07/13/95 Washington	HUGH 12/05/00 (94)	A plastic anemia Dr.	q2	08/02/95	Teri A.
25071M 07/10/95 Washington	CARL 03/17/09 (86)	Sm Cell Clea. Lymphoma Dr.	q2	07/26/95 Died 08/02/95	Lynn C.
25069M 07/03/95 Norman	JETTIE 06/09/13 (82)	Metastatic intrabdominal CA Dr.	q2	08/02/95	Calvin
250681 06/27/95 Purcell	HOBERT 10/17/31 (63)	Gleoblastoma Dr.	q2	07/26/95	Calvin/PC
25065M 06/16/95 Norman	GENE 06/11/11 (84)	Lung CA Dr.	q2	07/26/95 Died 07/23/95	Teresa
25064 I 06/13/95 Norman	WYNOMA 02/15/95 (83)	ES Dementia Dr.	q2	07/26/95	Lynn C.
25059M 06/05/95 Norman	ANNA 04/21/11 (84)	CHF Dr.	q2	08/02/95	Lynn C. Mary R.

Appendix D

INTERDISCIPLINARY TEAM PLAN OF CARE

- Initial review
- Update

PATIENT: _____ M.R. #: _____ P.C.G.: _____ DATE: _____	1. FREQUENCY OF REVIEW (dates of review) _____ _____	2. DIAGNOSIS _____ _____
3. VITAL SIGNS B/P: _____ PULSE: _____ RESP.: _____	5. MEDICATIONS: _____ _____ _____	
4. SUPPLIES & EQUIPMENT: _____ _____		

PROBLEMS	INTERVENTIONS
<p>6. PAIN SCALE: 1 2 3 4 5 5= WORST</p> <p>GOALS Patient will express relief of pain on severity level within 48 hours, and control within 2 weeks.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Monitor levels of pain and document. <input type="checkbox"/> Titrate medication and dosage PRN according to MD instructions. <input type="checkbox"/> Instruct pt/family on route, dosage, and medication side effects. <input type="checkbox"/> Monitor effectiveness of medication and interventions. <p>Other: _____</p>
<p>7. NUTRITION / HYDRATION Scale: 1 2 3 4 5</p> <p>GOALS Patient will achieve optimal nutritional status according to limits of disease process.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Instruct pt/family on: <input type="checkbox"/> High protein, High CHO dietary supplement. <input type="checkbox"/> Benefits of small frequent feedings. <input type="checkbox"/> Diet and any restrictions and how to feed patient. <p>Other: _____</p>
<p>8. NAUSEA & VOMITING Scale: 1 2 3 4 5</p> <p>GOALS Patient will express decrease of nausea and vomiting within 48 hours.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Monitor frequency and causative factors. <input type="checkbox"/> Medicate as ordered and evaluate effectiveness. <input type="checkbox"/> Instruct patient/family on dietary and medication regime. <p>Other: _____</p>
<p>9. RESPIRATORY COMPROMISE Scale: 1 2 3 4 5</p> <p>GOALS Patient will be free of respiratory distress and infection.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Assess respiratory rate, pattern, secretions and lung sounds. <input type="checkbox"/> Observe for respiratory distress/congestion. <input type="checkbox"/> Elevate head of bed. <input type="checkbox"/> Medicate as ordered. <input type="checkbox"/> O2 as ordered and instruct pt/family in O2 use and safety measures. _____ L/min <input type="checkbox"/> Continuous via _____ <input type="checkbox"/> Instruct on relaxation/energy conservation techniques. <p>Other: _____</p>
<p>10. ALTERATION IN BOWEL PATTERN Scale: 1 2 3 4 5</p> <p>GOALS Patient will have BM at least every 2-3 days.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Check for impaction, disimpact PRN. <input type="checkbox"/> Medicate/treat as ordered and evaluate. <input type="checkbox"/> Instruct pt/family in effective bowel regimen/ostomy care. <input type="checkbox"/> Instruct on diet, medications, treatments and care needed to maintain regular elimination. <p>Other: _____</p>

PT. NAME: _____ DATE: _____

PROBLEMS	INTERVENTIONS
<p>11. ALTERATION IN BLADDER ELIMINATION PROCESS Scale: 1 2 3 4 5</p> <p>GOALS Patient will maintain adequate urine output within disease output limitations.</p>	<p><input type="checkbox"/> Assess patterns, amount, and frequency of urination. <input type="checkbox"/> Keep skin clean and dry. <input type="checkbox"/> Condom cath PRN and foley care <input type="checkbox"/> Instruct pt/family in: <input type="checkbox"/> Peri care <input type="checkbox"/> How to irrigate foley <input type="checkbox"/> How to empty foley bag <input type="checkbox"/> Keep skin dry. Other: _____</p>
<p>12. IMPAIRED PHYSICAL MOBILITY Scale: 1 2 3 4 5</p> <p>GOALS Patient will maintain optimum level of functioning.</p>	<p><input type="checkbox"/> Assess patients present and potential level of functioning. <input type="checkbox"/> Instruction to be given to pt/family: <input type="checkbox"/> ROM and Light exercises <input type="checkbox"/> Good body mechanics <input type="checkbox"/> Transferring <input type="checkbox"/> Assisting w/ ambulation therapy <input type="checkbox"/> Instruct caregiver in safety measures pertinent to patient to include: _____ <input type="checkbox"/> Explore resources for assistance to meet needs <input type="checkbox"/> List DME _____ Other: _____</p>
<p>13. ALTERATION MENTAL/ NEURAL STATUS Scale: 1 2 3 4 5</p> <p>GOALS Patient will be maintained in safe environment through changes in mental status.</p>	<p><input type="checkbox"/> Monitor changes in mental consciousness and levels of communication. <input type="checkbox"/> Assess level of ability to follow directions. <input type="checkbox"/> Medicate as ordered and monitor effectiveness of meds. <input type="checkbox"/> Instruct family in safety instructions to include: _____ <input type="checkbox"/> Instruct on communication techniques, control of stimuli, & reality orientation. Other: _____</p>
<p>14. ALTERED CARDIAC/CIRC. FUNCTION/FLUID VOLUME DEFICIT Scale: 1 2 3 4 5</p> <p>GOALS Patient will function optimally within limits of disease process.</p>	<p><input type="checkbox"/> Assess B/P, pulse rate, strength and rhythm. <input type="checkbox"/> Assess activity tolerance. <input type="checkbox"/> Teach energy conservation. <input type="checkbox"/> Assess for fluid retention. <input type="checkbox"/> Evaluate effectiveness of medicine regime. Other: _____</p>
<p>15. COPING OF PATIENT Scale: 1 2 3 4 5</p> <p>GOALS Patient verbalizes feelings on death and dying and establish effective communication with Hospice staff.</p>	<p><input type="checkbox"/> Explore feelings and thoughts regarding death. <input type="checkbox"/> Provide emotional support. <input type="checkbox"/> Promote positive adaptation to dying process. Other: _____</p>
<p>16. COPING OF FAMILY/CARE GIVER Scale: 1 2 3 4 5</p> <p>GOALS Family verbalizes feelings on death and dying and establish effective communication with Hospice staff.</p>	<p><input type="checkbox"/> Provide active listening and support. <input type="checkbox"/> Encourage verbalization of feelings <input type="checkbox"/> Promote positive adaptation to dying process. Other: _____</p>

PT. NAME: _____ DATE: _____

PROBLEMS	INTERVENTIONS
<p>17. ALTERATION IN SLEEP PATTERN Scale: 1 2 3 4 5</p> <p>GOALS Patient will express adequate periods of sleep and rest</p>	<p><input type="checkbox"/> Assess patients previous sleep patterns and present sleep disturbances. <input type="checkbox"/> Medicate as ordered and monitor effectiveness. <input type="checkbox"/> Instruct patient/family in: <input type="checkbox"/> Medication regime <input type="checkbox"/> Possible side effects <input type="checkbox"/> Relaxation techniques</p> <p>Other: _____</p>

<p>18. ALTERATION IN SKIN INTEGRITY Scale: 1 2 3 4 5</p> <p>GOALS Skin integrity will be maintained.</p>	<p><input type="checkbox"/> Identify involved sites and assess tissue condition. <input type="checkbox"/> Use egg crate mattress/sheepskin. <input type="checkbox"/> Use air pressure mattress. <input type="checkbox"/> Turn & position for comfort at least every 2 hours. <input type="checkbox"/> Monitor status for signs of pressure q visit/shift. <input type="checkbox"/> Instruct pt/family in assessing skin for pressure areas daily. <input type="checkbox"/> Instruct pt/family in skin care techniques.</p> <p>Other: _____</p>
--	--

COMMENTS: _____

Nurse _____ Signature _____ 2nd IDT Member _____ Signature _____

HOME HEALTH AIDE EVALUATION

ARE PT/FAMILY SATISFIED WITH CARE? YES NO
 IS NURSING HOME SATISFIED WITH CARE? YES NO
 IS AIDE FOLLOWING ASSIGNMENTS IN A SAFE MANNER? YES NO

PROBLEMS ENCOUNTERED: _____

EVALUATION OF AIDE'S PERFORMANCE: POOR FAIR GOOD EXCELLENT

RN RECOMMENDATIONS: _____

REVIEWED BY: HHA: _____ DATE: _____

RN: _____ DATE: _____

Appendix E

BEREAVEMENT ASSESSMENT AND PLAN OF CARE

Patient Name _____ ID# _____

Admit _____ DOD _____ DOB _____ Office Location _____

Primary Bereaved _____ Relationship _____

Address _____ Telephone _____

RISK ASSESSMENT: Check YES, NO, or UNKNOWN for each.

	Yes	No	Unknown
is bereaved free of other family responsibility?	_____	_____	_____
is there adequate financial provision for bereaved?	_____	_____	_____
Was the family able to share feelings?	_____	_____	_____
is this the only current life crisis? if NO, explain:	_____	_____	_____
is there an adequate support system?	_____	_____	_____
is the bereaved believed to be free of suicidal ideation?	_____	_____	_____
is the bereaved believed to be free of problems with substance use/abuse?	_____	_____	_____

_____ Add name to Bereavement mailing list

SIGNATURES: _____ Date _____

Chaplain _____ Social Worker _____

Nurse/PCC _____

04/95

Appendix F

AS DEATH DRAWS NEAR

The following are descriptions of some of the signs and symptoms of approaching death. Not all of these symptoms will appear at the same time and some of them may never appear at all. Some may arise a few hours before death while others may be present for several weeks prior to death.

Our hope is that by sharing this information with you it may help alleviate some of the common fears and anxieties of caregivers in a difficult time. We have included some suggestions to help you in helping your loved one feel more comfortable as death draws near.

NUTRITIONAL CHANGES

- Food is the way in which we all energize our bodies and sustain our lives, however the dying process does not require nutrition. As death approaches there is a decreased need for food and fluids as the body conserves its energy for bodily processes. Dehydration is a natural and painless process. It reduces symptoms of swelling, vomiting, and the need to urinate. As death approaches swallowing often becomes more difficult.

WE SUGGEST that you provide light meals with high caloric and protein content. Liquid supplements, such as "Ensure", may be preferred over solid foods. Soft foods, such as oatmeal, pudding and ice cream may be easier for the patient to digest. Semi-liquids, such as milk shakes, juice, and Jell-O are often easier to swallow. Remember to give food in small amounts, elevating the head of the bed while eating. Forcing food or fluids may only increase the anxiety and discomfort for the patient. It's okay not to eat or drink.

BOWEL AND BLADDER CHANGES

- A decrease in urine output may be evident. If the patient has a bladder catheter the urine may appear dark, cloudy, or contain sediment.
- Patients often experience a loss of control of bowel and bladder functions.

WE SUGGEST that you place waterproof pads under the patient and use hygiene techniques. This will help the patient remain comfortable as well as preventing odor and skin tears. Try to remember that loss of bowel and bladder control is often extremely embarrassing to the patient. Attempt to bathe and clean her/him with care and dignity.

RESPIRATORY CHANGES

- Breathing patterns often change. Breathing may become more labored with respirations becoming more rapid and often more shallow. Respirations may increase from normal rates of 16-20 per minute, to 40-50 breaths per minute.
- Respirations frequently decrease as well, often to as few as 6-9 per minute. The patient may experience periods of apnea (when breathing stops completely for as many as 10 to 45 seconds before resuming).
- You may notice puffing or blowing of the lips when the patient exhales. These are all common signs of impending death.
- Oral secretions may become more profuse and collect in the back of the throat creating a "rattly" sound in the lungs and/or upper throat.

WE SUGGEST that you elevate the head of the bed slightly. These events are the normal course of events and while they may cause anxiety for patient and caregivers, it is not painful for the patient. It is important to remain as calm as possible so as not to alarm the patient.

SENSORY CHANGES

- The patient may experience a decreased clarity of hearing and or vision.

WE SUGGEST that you keep the room well lit, and speak to the patient from the head of the bed. Remember that hearing is often the last of the senses to cease functioning and may remain intact until death. Therefore do not say anything in front of the patient that you do not wish him/her to hear. Remember that touching is often the best communication when words and conversation are not possible.

- The lower jaw may relax resulting in symptoms of dry mouth.

WE SUGGEST that you keep the patient's mouth moist. Give the patient ice chips or offer small drops of water. Artificial saliva is available and often comforts the patient.

- The eyelids may remain slightly open and the eyes may have a glassy look. At times patients have increased tearing.

WE SUGGEST that you use a humidifier in the room and/or moist cloths on the eyes. There are also a number of products on the market for keeping the eyes moist.

SKIN CHANGES

- The arms and legs of the patient may become cool while the underside of the patient's body sometimes becomes darker and purplish in color.
- The hands, knees and feet of the patient may become mottled or blotchy.
- The skin may appear pale in color and there may be increased perspiration and a 'clammy' feel of the skin.

WE SUGGEST that you keep the patient warm without using electric blankets which may burn the tender skin of the patient. Change linens as needed to keep the patient dry. Turn the patient frequently to prevent skin breakdown.

MOBILITY CHANGES

- Patients often experience decreased sensation and power of motion and reflexes are often lost, first in the legs and then in the arms.

WE SUGGEST that you help the patient with daily activities and protect them from falling. The use of a wheelchair and a bedside commode may be helpful. When the patient is no longer able to get out of bed we suggest that the patient be turned every two hours to prevent pressure and skin breakdown.

PSYCHOLOGICAL CHANGES

- Sleep will be more frequent and the patient may become more difficult to arouse. This may be the first change noticed and is a result of changes in the body's ability to function.

WE SUGGEST that you plan your time with the patient when he/she seems more alert.

- The patient may become more withdrawn and display a loss of interest in the world around them. This may also extend to people, including loved ones.

WE SUGGEST that you remember that this is a common occurrence and to not take it as a personal rejection.

- The voice of the patient will often weaken and the patient may talk less.

WE SUGGEST that you avoid tiring the patient with prolonged visits and conversations.

- Patients may experience increased confusion about time, place and the identity of friends, relatives and other familiar people.

WE SUGGEST that you mention the day and time to the patient frequently. Be sure to identify yourself when you enter the room and refer to people in the room by name.

- Patients may experience increased restlessness and pulling at their bed linens and clothes.

WE SUGGEST that you speak calmly and with reassurance to the patient. Try not to startle or frighten the patient.

- Patients may report vivid dreams or visions. They may also report seeing people or things not visible to others. This may represent a life review of one's history. Or, it may indicate the patient's reflection on meaningful past relationships or the anticipation of being reunited with loved ones who have preceded them in death or with religious spirits.

WE SUGGEST that you attempt to listen with empathy and to not discount this experience because it is real to the patient. Reassure yourself and the patient that this is a common occurrence.

- Sometimes a patient may experience an increase in energy. They may appear more alert and their appetite may return. They may also have increased interest in interaction with others.

WE SUGGEST that you celebrate these times and honor this special gift as a chance to finish any unfinished business you may have with the patient.

AS DEATH DRAWS NEAR

As death draws near, we all experience different feelings and levels of anxiety. We hope that these suggestions may help you find some level of comfort during this difficult time.

If at any time you have other concerns or questions, do not hesitate to call the hospice office. Our staff is available 24 hours to assist our patients and their families in any way possible.

Appendix G

Signs of Death

- . No breathing
- . No heartbeat
- . Loss of bowel and bladder control
- . No response to shaking or shouting
- . Eyelids slightly open
- . Eyes fixed
- . Jaw relaxed and mouth slightly open


APPENDIX B

OFFICE OF RESEARCH ADMINISTRATION

The University of Oklahoma
Norman Campus

MEMORANDUM

TO: Jennifer Gourley, Curriculum Advisor
Graduate College

FROM: Karen M. Petry, Director 
Office of Research Administration

DATE: December 3, 1997

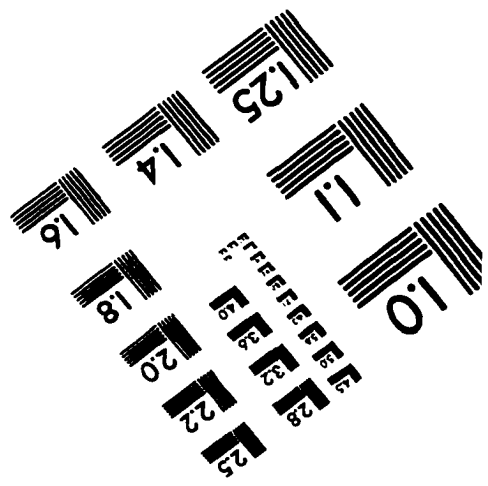
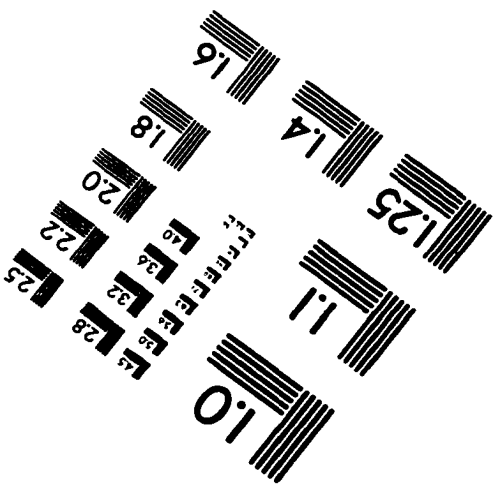
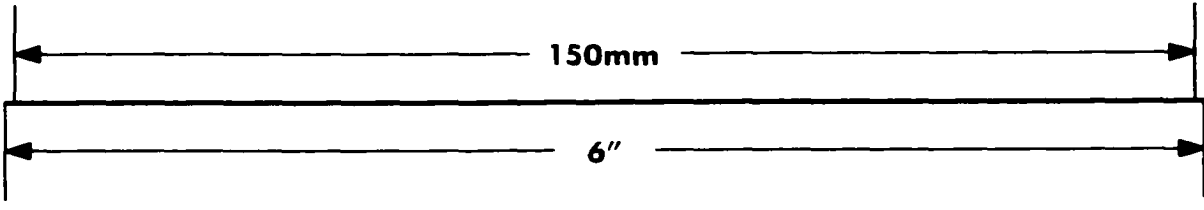
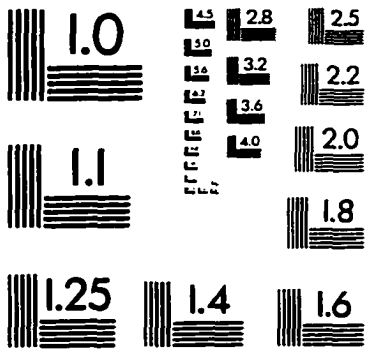
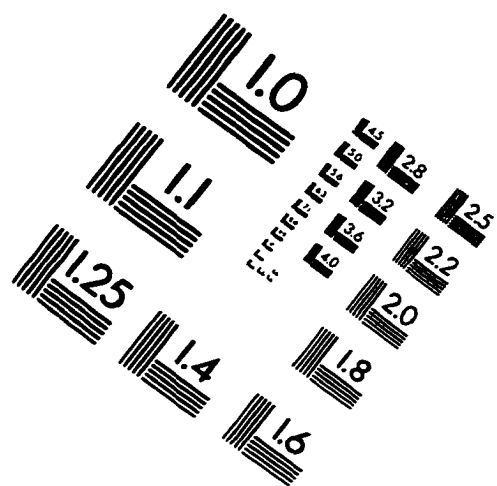
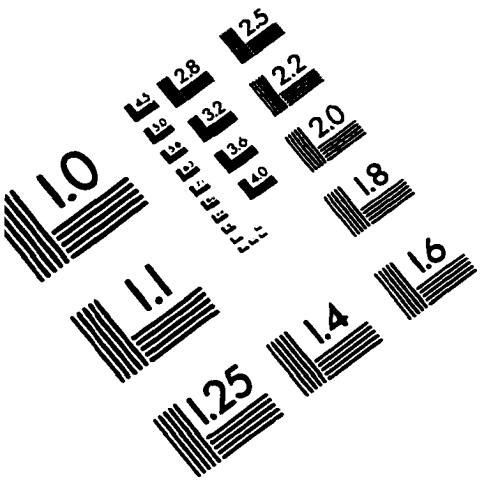
SUBJECT: IRB-Review of Use of Human Subjects
In Dissertation Research Project (98-105)

This is to confirm that Karl V. Winton's study, "Speaking About Death: An Ethnography of a Community Hospice," has been reviewed by the Institutional Review Board, Norman Campus. This study meets the criteria for consideration under the exempt from Board review category.

Please contact me if you require any additional information regarding this approval.

cc: Dr. E. Laurette Taylor, Chair, IRB-NC
Dr. Lawrence Wieder, Faculty Sponsor, Communication
Karl V. Winton, Principal Investigator, Communication

IMAGE EVALUATION TEST TARGET (QA-3)



APPLIED IMAGE, Inc
1653 East Main Street
Rochester, NY 14609 USA
Phone: 716/482-0300
Fax: 716/288-5989

© 1993, Applied Image, Inc., All Rights Reserved