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RESPIRATORY SIGNS OF THE TERMINALLY ILL PATIENT DURING THE DYING PROCESS

THE UNIVERSITY OF ARIZONA

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RESPIRATORY SIGNS OF THE TERMINALLY ILL PATIENT DURING THE DYING PROCESS

by

Stephanie Ann Foster

A Thesis Submitted to the Faculty of the

COLLEGE OF NURSING

In Partial Fulfillment of the Requirements
For the Degree of

MASTER OF SCIENCE

In the Graduate College

THE UNIVERSITY OF ARIZONA

1983
STATEMENT BY AUTHOR

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Katherine J. Young  April 12, 1963
Associate Professor of Nursing
DEDICATION

To Aníbal Mejía in appreciation of his unflagging optimism and generosity.
ACKNOWLEDGMENTS

I wish to express my appreciation to those persons whose guidance and support made possible the completion of this thesis.

A very special thank you goes to my thesis chairperson, Dr. Katherine Young, who provided encouragement and expertise. I also wish to thank committee member Gayle Traver, R.N., M.S., for her valuable insights, and Carolyn Murdaugh, R.N., Ph.D., for her critique and confidence.

To the staff at the Hospice Unit at St. Mary's Hospital who gave their time, I wish to express my appreciation. To the Hospice families whose questions inspired this research goes my deepest gratitude and respect.
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This was an exploratory/descriptive study designed to identify and describe the respiratory signs of the terminally ill during the dying process.

A convenience sample of ten terminally ill patients from a hospice unit at a local hospital participated in this study. Observations were made within 24 hours of admission to the hospice unit and within 24 hours of clinical death of the patient to determine the presence or absence of 11 respiratory signs during the dying process.

The findings indicated that:

1. Respiratory signs traditionally associated with imminent death sometimes occurred a number of days before clinical death of the patient.

2. Neither very low respiratory rates nor dramatic fluctuations in respiratory rate during the course of a few hours always indicated imminent death.
CHAPTER 1

INTRODUCTION

The death of a person which results from a brief, acute illness or an accident affects the remaining family members very differently from the death that results from a chronic, long-term disease process. In a case of accidental death or acute illness, there is no time for the family to absorb the reality of death or to observe the dying process. The event already has taken place, usually at some distance from the family, or unfolds in an intensive care unit where family members are peripheral during the efforts to save the patient. In the case of death from chronic disease, however, the family members of the terminally ill are cognizant of the inevitable nature of the coming sequence of events. The resolution of any terminal illness is, by definition, the death of the afflicted person (Miller, 1980). Thus, the members of the family have time to prepare themselves for the death. More importantly, family members usually are at the bedside close to the time of death and are witnesses to the dying process. They observe certain physical signs and symptoms of the dying process which they may not understand.

In settings specializing in the care of the terminally ill patient such as hospice units, intensive care and coronary care units, staff nurses routinely observe the physiological signs associated with
the dying process. Some of those signs include diaphoresis, mottling of the extremities, and a rise in core body temperature (Gray, 1976). Respiratory signs also are observed to be associated with the dying process. Respiratory signs are especially important since, frequently, they are the most obvious to the family at the bedside. They include: apnea, shortness of breath, Cheyne-Stokes respirations, and other abnormal breathing patterns.

The psycho-social processes involved in death and dying have been documented in the literature. Researchers have identified and described the five stages of dying (Kubler-Ross, 1969), and the three phases of personal response to the course of a fatal illness (Weisman, 1972). However, research describing the physiological process of dying is minimal.

**Statement of the Problem**

The problem for this study concerned the general lack of knowledge of the physiological aspects of the dying process. This lack is related to the unfamiliarity with dying and its signs and symptoms on the part of the staff nurses, except those nurses in specialty units such as hospice units and coronary or intensive care. Uneasy with dying, most staff nurses in general duty areas are unable to teach family members what to expect during the dying process. Thus, an important opportunity to provide support and comfort has been missed.

This study focused only on the respiratory signs of the dying process, since they are among the most visible to the family. The
questions of what respiratory signs were observed during the process of dying, whether the signs observed were common to the dying process, and whether or not a pattern or sequence of the signs existed was addressed.

Significance of the Problem

Families of the terminally ill often question specialty nurses about the signs and symptoms of the dying process which they happen to observe. Family members ask if the phenomena are normal during the dying process, if what they observe is painful to the patient, or if the patient is in any distress. In response, nurses routinely pass the information gathered from their daily observations on the process of dying to the families of their patients. These nurses have found that family members seem to be more in control of themselves during the difficult period prior to the death when they understand the usual signs they might expect to see and hear. Nurses know that anxiety frequently arises from a fear of the unknown, and have observed that the knowledge they give to the family seems to decrease the level of anxiety that family members experience (Barton, 1977).

Family members seem more willing to stay at the bedside of the patient when they are knowledgeable about the physiological sequences involved in dying. Some family members also find the confidence in themselves to honor a patient's wishes to die at home, certain that they are competent to provide the same quality of care to the patient that he would receive in a skilled care facility. Families who have been taught what to expect during the last few days before a death seem more
able to provide comfort and support to each other, and to the patient. They seem to participate more fully in the dying process, and also experience a healthier resolution of their grief after the death.

Increasingly, patients themselves are asking nurses about the dying process. They want to know how they will die, and what are the changes that will occur in their bodies before death (Diggory and Rothman, 1961). They wonder if they will experience pain as death approaches, if they will experience hemorrhage, violent choking, or a loss of physical and mental control (Barton, 1977). Thus, for both patients and their families, accurate information about the process of dying is needed.

The experiential knowledge painstakingly gathered over a number of months or years, and provided by specialty nurses to terminally ill patients and their families, is valuable, without a doubt. However, research documenting the physiology of the dying process has not been undertaken. As a result, many nurses who staff medical and/or surgical units, pediatric units, and obstetrical units across the country, and who experience death infrequently, are uncomfortable caring for patients who have no hope of recovery. Research has documented the reluctance of hospital nurses to enter the rooms of the dying, or to answer their call lights (Sudnow, 1970). Competent nurses unfamiliar with death may disagree with colleagues about the onset of Cheyne-Stokes respirations in their terminal patients, or about whether or not a patient's respirations actually have ceased.
Only recently has the importance of an interaction between the nurse and the dying patient and his family been addressed in nursing textbooks, and rarely is the existence of a physiological process of dying mentioned (Luckmann and Sorensen, 1974). Clinically, students at schools and colleges of nursing are given little guidance about what to expect when observing their first death. The student might receive lectures on death and dying, but he or she has no real opportunity to work through feelings or to have structured, supported actual experiences with dying patients (Barton, 1977). Inhouse seminars for graduate nurses on death and dying now are common in most hospitals; however, inservice education on the physical process of dying is not included in the curriculum. Thus, nurses, as well as terminally ill patients and their families, will benefit from research studies on the topic of dying, studies that document the physiological process of dying.

**Purpose of the Study**

The purpose of the study was to identify and describe the respiratory signs of terminally ill patients during the dying process.

**Conceptual Orientation**

The conceptual orientation for this study focuses on anticipatory care as a concept in family education, and the significance of anticipatory guidance as it relates to educating family members of the terminally ill about the observable signs of the dying process.
Chronologically, as one conceptualizes the model (see Figure 1), one must first assume the existence of the concept of terminal illness. A terminal illness, by definition, results in the dying of the individual; it results in a process of dying (Evans, 1963; Fuerst, Wolff and Weitzel, 1974). This process of dying is characterized by certain psychosocial aspects (Kübler-Ross, 1969), and certain physical signs. The physical signs of the dying process are not well defined, but preliminary studies and personal experience reveal that they might include increased core body temperature, diaphoresis, coma, increased muscular flaccidity (Gray, 1976). Also thought to be associated with the dying process are certain respiratory signs such as Cheyne-Stokes respirations, apnea, stertorous breathing (the death rattle), and shallow breathing, among others (Luckmann and Sorensen, 1974). Little information exists regarding the extent to which these physical signs do appear in dying patients. No information exists regarding whether or not these physical signs occur at a certain point before death, or if they appear in a certain pattern. Little is known about whether or not diagnosis of the patient affects the signs that appear close to the time of death.

If one could establish that certain physical signs are in fact exhibited during the dying process, or if there is a pattern in which the signs occur, then one would have information with which to teach the families of the terminally ill. These physical signs, taught to family members via anticipatory guidance, using the concept of anticipatory care, might alert them to the imminence of the death of the patient, and they might be better able to plan for the death event. In addition,
Figure 1. Model of conceptual orientation (framework for model based on work by Gibbs, 1972).
family members might be more in control of themselves during the dying process (Hine, 1979). The family of the dying patient might be more comfortable, less anxious, and be able to resolve their grief more easily, than if they remained ignorant of the course of the dying process (Barton, 1977).

This study involved identifying the respiratory signs that occur during the process of dying. These respiratory signs are obvious to family members of the dying, are a discrete body of signs lending themselves to study, and are easily detectable by observation. Using the concept of anticipatory care, the information about respiratory signs, together with knowledge about the physical signs of other body systems, might routinely be taught to family members of the terminally ill.

The following sections of the conceptual orientation explain in more detail the levels which appear on the model previously presented in Figure 1. The concept of anticipatory care is defined, and is differentiated from the teaching technique of anticipatory guidance. Material regarding the importance of identifying physical signs of the dying process, especially respiratory signs, is included, in addition to material on the need for teaching this information to family members of the terminally ill.

Anticipatory Care

According to Pridham, Hansen and Conrad (1977: 1077), anticipatory care is:

... a broadened and enriched "preventive medicine" in which the notion of "health" comprises a more diverse set of issues
than the prevention of disease or illness as such. "Health" in this context means simply the capacity of the individual to adapt successfully and to maintain function despite whatever stressors he or she may encounter.

The concept of anticipatory care concerns the preparation of an individual, family or community to encounter and adapt to "anticipatable stressors." These stressors may be physical, biological, emotional or psychosocial. The assumption underlying the concept of anticipatory care is that the outcome of health services is improved if the clinician and the patient are able to anticipate events or situations of importance. The patient fares better if he succeeds in mobilizing a capacity to cope more effectively with potentially harmful situations or those which prevent achievement of a desired goal (Pridham et al., 1977).

Anticipatory Guidance

Utilizing the concept of anticipatory care, direction and guidance are given to clients by health care professionals to teach them what to expect in advance of a stressful procedure such as surgery, or an event such as childbirth. This "preparatory communication," or advice, is known as anticipatory guidance. The technique of anticipatory guidance seems to work well with the "ordinary or frequent and recurring events of life," such as the "caretaking of newborns and elderly persons, the process of recovering from a life-threatening illness, and grieving" (Pridham, 1977: 1079). Anticipatory guidance, or preparatory communication, has also been found helpful in the area of family responses to chronic illness (Miller, 1980). According to Miller, families with terminally ill members need to understand the
relationship between physical and psychosocial consequences. The health professional can promote this understanding.

If anticipatory guidance is effective in helping families of the terminally ill, one might well assume that anticipatory guidance could be useful in teaching those families what to expect during the dying process. Areas of concern might focus on the physical signs of approaching death, in addition to the psychosocial aspects that usually are mentioned.

**Signs of the Dying Process**

Around the turn of the century, physicians concluded that all the tests so far devised to determine if death had occurred in a certain patient, were inconclusive, with the single exception of putrification (Carrington, 1911). As late as 1969, a physician investigated death, outlining six criteria for determining the time of death. He noted, however, that the criteria might not be absolute for children, or for adults in a state of hypothermia or severe intoxication, especially from drugs (Wright, 1969). This difficulty in establishing absolute criteria for the time of death probably is one of the reasons so few people have studied the phenomenon.

The signs of the dying process, however, have merited some attention by authors. Albano (1969), Luckmann and Sorensen (1974), Fuerst et al. (1974), Gray (1976), and Walker (1977) have identified a few signs of the dying process, although no research studies per se have focused on this topic.
Physical signs of the dying process are important in alerting family members to the trajectory of the terminally ill patient. To the family, knowing approximately how long the patient will live is necessary in order to advise out-of-town family members when to gather. Knowing what to expect gives the family a sense of control over the uncertain events of the dying process.

Physical signs of the respiratory system are especially significant since respiratory signs are so obvious to the family. Even the untrained observer recognizes that apnea, Cheyne-Stokes respirations and stertorous breathing are abnormal breathing patterns. However, before nurses can teach family members which signs they might expect to observe during the dying process, investigators must first establish that certain physical signs indeed are associated with dying and investigators must observe terminally ill patients during the dying process, and note the presence or absence of the respiratory signs traditionally thought of as associated with imminent death. Investigators must catalogue any pattern of the appearance of respiratory signs during the dying process. Observers must note any changes in respiratory rate, and where in the process those changes occur. Then the investigator might draw conclusions about whether or not any predictions concerning the physical signs of the dying process can be made.

**Family Education Regarding Respiratory Signs**

In teaching the family of the terminally ill those physical signs which usually appear during the dying process, the nurse must
understand that the family member observes the same signs that the nurse and the physician observe. To the health care professional, the detailed history, incorporating the signs and symptoms of pathology, and laboratory testing, yield the diagnosis of a disease. A physical sign can be seen, felt, or heard by the observer (DeGowin and DeGowin, 1971). Among the methods used to detect the signs of pathology by a professional, inspection (seeing) and auscultation (hearing) also are utilized routinely by the layperson.

Inspection, or observation with the unaided eye, is employed by family members of a dying patient to attempt to determine changes in the patient's condition. Inspection depends upon the knowledge of the observer, and humans tend to see things that have meaning for them (DeGowin and DeGowin, 1971). Observed changes in the condition of a terminal patient have significant meaning to family members (Hine, 1979). However, most family members do not know how to interpret the changes they observe.

The act of hearing without the use of a stethoscope (direct auscultation or immediate auscultation) is also utilized by laypersons in gathering pertinent information. Words, coughs, groans and gurgles all furnish information to the layperson. When the family member is uninformed about the meaning of detectable signs, however, he or she may misinterpret the data observed. This misinterpretation may have unfortunate results: the family member may either worry unnecessarily, or he or she might remain ignorant of the impending death of the patient.
Among the respiratory signs the family may detect by inspection and/or by direct auscultation are: the use of accessory muscles as an aid in breathing, nasal flaring, increased or decreased respiratory rate, shallow respirations, periods of apnea, hyperpnea, and Cheyne-Stokes respirations. Coughing, stertorous breathing (the "death rattle"), stridor, wheezing and gasping also might be observed.

Since signs and symptoms are manifestations of the presence of pathology, the observable signs listed above are indications of dysfunction; in this case, dysfunction of the ventilatory system. Pathology, or a disease state, "results in the disruption of the normal physiology of an organism, and a concomitant deterioration in function that renders the organism unstable or threatens its continued existence" (Gröer and Shekleton, 1979:184). Family members of the terminally ill may not understand physiology, but they are aware that the respiratory signs they observe are indications of pathology. They intuitively know that death will result; in terminal illness, the pathological condition cannot be corrected.

**Definitions**

**Dying Process:** The dying process refers to the period of time between 24 hours of admission to the hospice unit at a local southwestern hospital and death of the patient.

**Clinical Death:** Clinical death is the cessation of respirations and heart beat, with pupils fixed and dilated, and an absence of tendon reflexes.
**Terminally Ill Patient:** A terminally ill patient is any person meeting the criteria for entrance into the hospice unit at a local southwestern hospital not admitted for respite care or symptom control who has a probable trajectory of 48 hours to three weeks.

**Trajectory:** The trajectory of a terminally ill patient refers to the duration of his or her dying process. A trajectory of less than seven days is rapid.

**Summary**

By first assessing which respiratory signs actually are associated with the dying process, the hospice nurse is in a position to correct the misconceptions that family members may have about respiratory signs they may observe. Guiding, directing and advising, the hospice nurse can teach the family which respiratory signs they might expect to see as the patient goes through the process of dying. Soon after the admission of the terminally ill patient to the hospice unit, the nurse could describe the breathing patterns that family members might encounter; he or she could explain the significance of the groans and gurgles in terms of patient comfort. The nurse could describe which signs indicate that death may occur in hours or in days. By utilizing the concept of anticipatory care, the nurse can help family members prepare for the emotional stressors that they will encounter. In this way the nurse will be "mobilizing a capacity to [help family members] cope more effectively with [a] potentially harmful situation" (Pridham, 1977:1081).
CHAPTER 2

REVIEW OF THE LITERATURE

The review of literature includes discussion of terminal illness, the process of dying, physical signs of the dying process, and respiratory signs of the dying process. Also included is a discussion of the studies concerning anticipatory care, anticipatory guidance, educating the families of the terminally ill, and educating the families about the physical signs of the dying process.

Terminal Illness

The following subject matter is presented without substantial studies. Due to the sensitivity of the topics of death and dying, these areas have not lent themselves to investigation. However, many authors have expressed opinions about the areas of terminal illness and the process of dying.

The terminally ill person, by definition, will not regain physical wellbeing (Carey, 1975), and is viewed as being in the final stages of his life. The resolution of the terminal illness is, then, the death of the afflicted person (Miller, 1980). However, dying is not a medical phenomenon entirely. "The disease process, its symptoms, and its ramifications are clearly medical matters. [But] the impact of both the illness and impending death on the family structure and family finances are not, strictly speaking, medical matters" (Zimmerman, 1981: 15)
The terminal illness involves both the patient, who will die, and his family.

The Process of Dying

According to the traditional clinical criteria of death, a person was considered dead if, "in the announced opinion of a physician, based on ordinary standards of medical practice, he had experienced an irreversible cessation of spontaneous respirations and circulatory functions" (Thorup, 1974: videotape). In recent years, however, the definition of death has come to include the cessation of brain activity as well (Albano, 1969; Fuerst et al., 1974). Clinical death is separate from biological death, and clinical death always precedes biological death. Clinical death occurs at the bedside, when the heart stops beating and the person ceases to breathe, when the pupils remain fixed and dilated, and when there is absence of tendon reflexes (Albano, 1969).

Death is a gradual process, and biological speaking, occurs by degrees. The body retains certain biological activities for some time after clinical death occurs (Fuerst et al., 1974). The body itself may remain alive after death. There can be local death in a living body or local life in a dead body (Evans, 1963).

The progress of death depends on the varying ability of the tissues to live without oxygen (Fuerst et al., 1974). Oxygen lack due to circulatory failure is the ultimate cause of death (Luckman and Sorensen, 1974).
Physical Signs of the Dying Process

A search of the literature uncovered little information that details the physical signs of the dying process. No studies were found. However, in recent years an increased interest in physical signs has been noted, and authors of both medical and nursing textbooks and hospice literature have made generalizations and expressed opinions about the physical signs of the dying process.

Gray (1976) identified the following signs and symptoms of the dying process:

- Decreased sensation, motion and reflexes, usually beginning with the feet and legs
- Failure of peripheral circulation which is accompanied by a drenching sweat and a cool external body temperature
- Increased core body temperature
- Increased muscular flaccidity
- Decreased consciousness
- A turning toward a light source in the room
- Coma
- Apnea

Walker (1977) also identified coma as almost universally present prior to death, as well as apnea. Albano (1969) observed that the pulse may be weak, irregular, and hardly obtainable at times in the dying patient.
Respiratory Signs of the Dying Process

In addition to the signs of apnea reported by Gray (1976), authors have listed other respiratory signs of the dying process. Albano (1969) observes that respirations in the dying may be shallow and barely perceptible. Luckmann and Sorensen (1974) give the respiratory signs of the dying process as: irregular respirations, rapid and shallow respirations or very slow and stertorous respirations, and Cheyne-Stokes respirations. Fuerst et al. (1974) also assert that Cheyne-Stokes respirations occur commonly in the dying, that respirations may be noisy, and that the "death rattle" may be heard due to an accumulation of mucus in the respiratory tract.

Anticipatory Care

The concept of anticipatory care is an old one; as long as individuals who have survived difficult experiences have been advising others how to face similar circumstances, the concept of anticipatory care has been utilized. Anticipatory care is a concept which has been used by such nonprofessional organizations as La Leche League and Alcoholics Anonymous (Pridham et al., 1977). In addition, this concept has been useful in the maternal-child health care area for over 50 years (Foster, 1963).

According to Pridham et al. (1977: 1077), the focus of anticipatory care "which remains to be developed and refined has to do with issues that relate to aiding a specific individual (or family or community) to prepare for encountering and adapting to particular anticipat-
able 'stressors.'" These authors assert that, until the present, anticipatory care has not been amenable to either study or practice because of the nebulous nature of the variables and their relationships. Pridham et al. propose that these problems can be overcome if anticipatory care is viewed as a problem-solving process, which enables the client to make independent decisions, and create problem-solving strategies. To this end, they have designed a study to develop a problem-solving methodology for patients. Preliminary findings suggest that anticipatory care "is practical as a highly variable and limited process" (Pridham et al., 1977: 1081).

**Anticipatory Guidance**

Anticipatory guidance is one aspect of anticipatory care. The American Public Health Association described the clinical technique of anticipatory guidance in relation to mothers of infants and small children as "teaching the mother what to expect before she begins to worry or make mistakes" (APHA, 1955: 47). Anticipatory guidance is defined as "guidance, direction or advice to the patient and 'preparatory communication' prior to a diagnostic or treatment procedure" (Pridham et al., 1977: 1077).

Many authors seem to agree that anticipatory guidance is important in teaching families, especially parents; however, only a handful of studies actually have been conducted. Nurse midwives are utilizing the concept of anticipatory guidance to help parents anticipate difficulties with their infants rather than cope with problems after they
arise. Vanderzanden (1979) advocates the use of anticipatory guidance with postpartum mothers. She summarizes the current "state of the art" utilization of anticipatory guidance in teaching basic infant care to mothers, and encourages health professionals to begin this teaching in the prenatal period. Areas of focus for anticipatory guidance include: feeding, stools, remedies, colic, cord care, care of the circumcised penis, illnesses to expect, sleep patterns, and how to provide stimulation to the infant.

Caplan (1980: 680) reports the use of anticipatory guidance as an approach to preventive intervention in child psychiatry. He proposes the use of "crisis intervention for children and their families by anticipatory guidance . . . to provide individuals under stress with help with emotional reequilibrium and cognitive guidance," especially when a child is to be admitted to the hospital.

Authors Kinsbourne and Swanson (1980: 117) advocate the use of anticipatory guidance by physicians when learning and conduct problems are due to long-lasting developmental delays which cannot be cured. The authors state that anticipatory guidance "can forestall serious negative secondary effects on the child's personality development and on the family dynamics."

While not actually conducting research on anticipatory guidance, many authors specifically note the need for its use. D. P. Orr discusses the increased presentation of children who are victims of sexual abuse to the offices of primary care providers. He states that "post-examination counseling should include explanation of findings, legal
implications of sexual abuse, and anticipatory guidance about common psychological sequelae of abuse" (Orr, 1980: 1064). In a discussion of adolescent sexuality and the family, R. R. Jenkins (1982) advocates the use of anticipatory guidance by pediatricians in teaching parents of teenagers about normal adolescent sexuality. After a study comparing sixteen children and adolescents with extremely short stature secondary to hypopituitarism to a matched group of physically healthy peers, Drotar, Owens and Gotthold (1980: 66) state that "anticipatory guidance for children with extreme short stature might help facilitate more adaptive responses to the difficult and inevitable frustrations imposed by short stature." The investigators propose the "evaluation of interventions directed toward the enhancement of coping skills and life adjustment of children with short stature secondary to hypopituitarism as a focus for future research with this population" (Drotar et al., 1980: 66). At the conclusion of a study involving sexual enjoyment during pregnancy, investigators stated that "anticipatory guidance and informed counsel regarding sexual changes in pregnancy should be provided to help pregnant patients and their husbands adapt to the pregnancy and enhance their marital bonds" (Reamy et al., 1982: 327).

Broussard (1976), one of the few investigators to actually conduct research on anticipatory guidance, studied primaparas using closed circuit television. His study involved groups of primaparas, some of which received televised instruction regarding infant care. His findings were inconclusive, although the groups that received the televised
guidance were more positive in their perceptions of their infants at one month than the control group.

Reisinger (1980) studied physician-patient interactions in twenty-three pediatricians' offices to determine the time spent discussing potential health problems. The findings showed that anticipatory guidance constituted 8.7% of the total time. Pediatricians in group practice or partnership and those recently trained spent more time with patients and a greater part of their time in anticipatory guidance. The amount of time during the visit spent in anticipatory guidance varied with age of the patient, with the most time being spent with the patients of infants less than five months of age. Pediatricians spent an average of seven seconds with adolescents. The investigators suggest that pediatricians "reorient their priorities by addressing currently unmet health problems" (Reisinger, 1980: 892).

Wolfer and Visintainer (1975) used children undergoing stressful diagnostic and operative procedures as subjects. The investigators found that the number of behavioral upsets was reduced when many different sessions of a systematic program of anticipatory guidance were employed, as opposed to one "catchall" session.

**Educating Families of the Terminally Ill**

The topic of educating the family of the terminally ill is seen increasingly in the literature, although no studies per se were encountered. One author states that caregivers should take an active role in the education of the family living through the terminal illness of a
loved one. The caregiver, through the process of care, should not only attempt to anticipate those questions which might arise, but should repeatedly inquire whether or not the patient or his family has questions regarding the illness (Barton, 1977). Barton states that the family of a terminally ill patient has an intense need to communicate effectively with those persons involved in giving care. When the family is unable to gain access to caregivers who might provide information, they may feel a sense of isolation and separateness.

Some support is given to the assertion that the family may benefit on a long-term basis from intimate involvement in the illness, care, and death of the patient. A possible complicating factor in the grief process of the family may be the absence or isolation from the occurrences surrounding the death. This isolation from the death results in inadequate sensory perceptions for the acknowledgment of its reality (Barton, 1977).

Miller (1980) clearly advocates the use of anticipatory guidance as a tool when working with families of the chronically or terminally ill. She states that anticipatory guidance can effectively address the problems associated with chronic illness such as enmeshment versus disengagement, as well as aid in understanding the states of grief. Utilizing a problem-solving approach, families can be alerted to potential problems by discussing with nurses some of the problems family members conceivably will face.
No studies were found to be relevant to teaching family members about the signs of the dying process. However, both nurses and family members are aware of the need for this type of teaching. Hine (1979), the wife of a terminally ill patient who preferred to die at home, states, "families considering a home death need to know a few basic things about how to tell when death is imminent and what might happen at the moment of death. They also need to know how to tell when someone is dead" (Hine, 1979: 184). Hine states that she and her family did not know which symptoms indicated "a system shutdown" until the home practical nurse provided this information. The practical nurse described the signs of approaching death, mentioning "eyes that never closed all the way, a certain pattern of breathing that she described very accurately" (Hine, 1979: 183). However, the practical nurse seems not to have imparted this knowledge as part of a structured teaching program, but only in response to questions by the family. Hines states flatly that the information she and her family received "enhanced our sense of control over the situation immeasurably... now we knew the frightening things that could happen, and we knew we could handle them, whether they actually happened or not" (Hine, 1979: 183).

Nurses, too, are beginning to see the value of structured family education regarding the physical signs of the dying process. Ann Martin, a hospice nurse, discusses her teaching experiences in counseling the families of terminally ill patients. "Hospice nursing involves caring
for the family as much as for the patient. I . . . teach the family what signs to look for when death becomes imminent. These signs include a change in breathing, decreased urine output, mottled skin, and a change in pain status." She concludes, "participating in [the patient's] care helps [the family] begin the grieving process" (Martin, 1981: 130).

**Summary**

While no actual investigations of the process of dying, the physical signs or the respiratory signs of the dying process were uncovered, the assertions of various authors did provide a list of respiratory signs generally accepted to be associated with the dying process. No literature suggested a pattern to the appearance of the physical signs of the dying process, or suggested how long before the death these signs might appear. The literature does suggest that anticipatory guidance logically can and should be used with families of the terminally ill.
CHAPTER 3

METHODOLOGY

Method

Since little is known about the respiratory signs of the dying process, an exploratory-descriptive design was used for this study. An exploratory design is employed when no significant research in an area is discovered during a search of the literature. Thus, the research was broad-based in order to expose multiple facets of the problem. The goal of an exploratory study is to generate data that point out the concepts upon which to develop a conceptual framework, or hypotheses for testing in a subsequent study.

A descriptive design is utilized when the investigator has some idea about the concepts involved. Through past clinical experience in a hospice setting and in informal interviews with staff nurses on units where dying occurs frequently, the investigator gathered a number of the physical respiratory indicators that seem to be present during the dying process. Therefore, the data collection instrument reflects signs the investigator expected to find. In addition, an open-ended component was included to provide for other indicators which might be observed (Appendix A).
Sample and Setting

Ten individuals in the last phase of a terminal illness were observed at least two times after their admission to the inpatient hospice unit at a local hospital. The first observation period (admit check) occurred within 24 hours of the admission of the patient to the unit. The last observation period (check 3, or death check) took place within 24 hours of the clinical death of the patient. Three patients were observed at two midpoints (checks 1 and 2) during their trajectories, and seven patients were observed at one midpoint (check 1). No attempt was made to control for the difference in the trajectory of the subject, the disease state, age, sex, ethnic group, language, or socioeconomic differences in the subjects. A voluntary, convenience sample was employed.

Protection of Human Subjects

A proposal was submitted and approved by the Human Subjects Review Committee of the University of Arizona (Appendix B). Subsequently, the purpose of this study was explained to the administrative personnel at the hospice unit, and approval from the Human Subjects Committee at that southwestern hospital was obtained (Appendix C). In addition, the study was explained to nursing staff of the hospice unit on all three shifts, and approval was obtained from the Director of Nurses.

A written explanation of the study and the consent form were made available to each family who agreed to be part of the study (Appendix D). In order to establish rapport, to explain the study, and to obtain consent, the investigator made at least one extended visit to
each of the families during the days or weeks before the death. Each family was assured of confidentiality in the collection of the data and in the reporting of the findings. Most families preferred not to inform the terminally ill patient of the true nature of the study.

Data were collected solely by the investigator. The investigator visited or telephoned the hospice unit each day to ascertain the presence of new patients who were admitted and who were thought to have a trajectory of a few days to a few weeks. Consent of the family was obtained (see Appendix D), and the admission check data were collected within 24 hours of admission to the unit. Using the Respiratory Data Collection Instrument, the data were collected via observation only. Respiratory rate was noted, as was the presence of any of the signs on the instrument. Respiration rate per minute was counted at least twice. The investigator informally validated with hospice staff the presence or absence of the respiratory signs in a given patient. At times, hospice staff informed the investigator via beeper when a dramatic change in a patient's breathing occurred, and informed her of how typical the signs were for the preceding eight to 12 hours. When the condition of the patient was considered by the investigator to be stable, she spent approximately five minutes observing the respiratory signs. However, when the patient's condition was considered to be unstable, then observation time took up to one hour.

Respiratory Data Collection Instrument

The instrument, a checklist of observable respiratory signs, was designed by the investigator. The items were based on past clinical
observations, and a review of current literature. The 11 indicators in the data collection instrument were measured by observation. Criteria for recognizing the indicators follow:

1. **Cough:** A sudden, forceful, noisy expulsion of air from the lungs; may be single or paroxysmal (DeGowin and DeGowin, 1971).

2. **Stertorous Breathing:** Vibrations of secretions in the upper respiratory tract; gurgling, the "death rattle" (DeGowin and DeGowin, 1971).

3. **Stridor:** A high-pitched inspiratory whistling or crowing sound caused by passage of air through the partly closed glottis (DeGowin and DeGowin, 1971).

4. **Hyperpnea:** Deep, regular, sighing respiration, with or without increased frequency (Comroe, 1974).

5. **Shallow Breathing:** Less chest motion than previously noted.

6. **Cheyne-Stokes Respirations:** Cycles of gradually increasing tidal volume followed by gradually decreasing tidal volume (Comroe, 1974). Cheyne-Stokes respiration is characterized by alternating periods of hypoventilation and hyperventilation. In its typical form, an apneic phase that lasts for 15 to 60 seconds is followed by a phase during which tidal volume increases with each breath to a peak level, and then decreases in decrescendo fashion to the apneic phase (Fishman, 1980).

7. **Gasping:** Spasmodic inspiratory effort, usually maximal, brief, and terminating abruptly; may be rhythmic or irregular (Comroe, 1974).
8. **Apnea:** Cessation of respiration in the resting expiratory position (Comroe, 1974). Lasts for at least 10 seconds (Fishman, 1980).

9. **Accessory Muscles:** Use of the scaleni or the sternomastoid muscles as an aid to inspiration (Campbell, 1970). Observation of the excavation of the supraclavicular fossae also constitutes the use of accessory muscles.

10. **Nasal Flaring:** Flaring of the ala nasi.

11. **Respiratory Rate** was also measured, in addition to the indicators mentioned above. Respiratory rate was defined as the number of complete respirations (one inspiration and one expiration) counted in 60 seconds. The respiratory rate was measured with a wristwatch as the number of complete respiratory cycles (from the beginning of an inspiratory cycle to the end of an expiratory cycle) in 60 seconds. The presence of respiratory signs other than those listed by name on the data collection instrument was noted and described.

Face and content validity of the data collection instrument was sought through a review of items by the following faculty at the University of Arizona: Dr. Katherine Young, R.N., Penny Iles, R.N., M.S., Gayle Traver, R.N., M.S.N., and Marianne Schroeder, R.N., M.S. Revisions were made following this review.
Pilot Study

The revised instrument was then pilot tested with two terminally ill patients. The purpose of the pilot test was to establish the viability of the observational tool, and to ensure measurement accuracy of the signs. At the end of the pilot study, a blood pressure measurement and pulse measurement were dropped from the instrument, after a discussion with hospice administration and staff. Staff expressed reservations about disturbing the dying patient to take these measures. The investigator agreed that blood pressure and pulse data were extraneous to the study, and would not yield any data significant to the purpose. In the interest of dignity and patient comfort, these items were dropped from the instrument. Deletion of the items also ensured that the subject would not be touched physically by the investigator, a factor which was significant in obtaining consent of the families to include their family member in the study. Shortness of breath also was dropped from the instrument, as it proved to be a subjective symptom and was difficult to measure.

Analysis of Data

Descriptive statistics were used to analyze the data. Frequencies of patients exhibiting each sign on the Respiratory Data Collection Instrument were obtained.

Errors and Limitations

Threats to external validity include the following:

1. The small sample size, not necessarily representative of all
patients dying of terminal disease, constitutes a major threat to the external validity of the study.

2. The voluntary, convenience sample, which might have been atypical of the total terminally ill population, made any generalizations difficult.

3. The investigator did not attempt to control extraneous variables such as age, sex, ethnic group, language, socioeconomic group, disease stage, and trajectory of the patient.

4. No attempt to control the administration of drugs such as atropine to decrease secretions, or morphine sulphate to relieve pain was made by the investigator.

Threats to the internal validity include the following:

1. The investigator used a tool which has unknown reliability and validity.

2. The bias and personal judgment in data collection and analysis of the investigator cannot be overlooked.

Summary

The respiratory signs of ten terminally ill subjects were observed at least two times between their admission to the hospice unit, and the occurrence of the clinical death of the subject. The presence or absence of 11 respiratory signs was observed, including a measurement of respiratory rate per minute. Descriptive statistics were used to analyze the data.
CHAPTER 4

PRESENTATION AND ANALYSIS OF DATA

Discussion in this chapter concerns the findings related to the study's purpose of identifying and describing the respiratory signs and symptoms of terminally ill patients during the dying process. The first section describes the characteristics of the sample. Subsequent discussions include data concerning respiratory rate, respiratory signs by subject, and the frequency of each respiratory sign.

Characteristics of the Sample

Ten terminally ill patients all had met the entrance criteria for the hospice unit at a local southwestern hospital. In addition, these ten subjects were chosen by the investigator based on their projected trajectory of a few days to a few weeks. The most rapid trajectory was three days; that is, within three days after admission the subject expired. The slowest trajectory of a subject was 18 days, with the mean trajectory falling at eight days. Six subjects died within six days of admission; four subjects died within eight to 18 days of admission.

While check 3, the death check, by definition took place within 24 hours of clinical death, in fact all 10 subjects were within 19 hours of clinical death. For eight subjects, check 3 took place
within 12 hours of clinical death, and for two subjects, check 3 occurred within a few minutes of clinical death.

Seven subjects were male, and three were female. Subjects ranged in age from 41 to 86 years, with a mean age of 73 years. All subjects were Caucasian, and all families were English-speaking.

Diagnoses for the 10 subjects were almost exclusively carcinoma. Nine subjects (90%) had a primary diagnosis of cancer. Forty percent had a primary diagnosis of lung cancer, while the other 50% were as follows: cancer of the pancreas, cancer of the stomach, cancer of the larynx with metastases to the lungs and esophagus, cancer of the colon, and cancer of the prostate. One subject (10%) had a primary diagnosis of sepsis, with secondary diagnoses of spine disease, congestive heart failure, pathological fractures, and pulmonary embolism (see Table 1).

**Role of the Investigator**

The investigator in this study, a registered nurse who has worked in a staff capacity in a hospice setting, chose an expanded role. The investigator made herself available to the family of the terminally ill patient to explain the meaning of respiratory signs the family observed, in addition to collecting respiratory data. Often the discussion of the respiratory signs led to an explanation of other signs noted by the family; and many times a discussion of larger issues, both ethical and metaphysical, occurred. The families seemed eager to relate their questions, their fears, and their knowledge, painfully gained through previous personal experience with a dying family member.
Table 1. Sample characteristics: by age, sex, diagnosis, and trajectory.

<table>
<thead>
<tr>
<th>Sex</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males = 7</td>
<td>Males: 41-86 years; mean = 70.7</td>
</tr>
<tr>
<td>Females = 3</td>
<td>Females: 68-86 years; mean = 78.3</td>
</tr>
<tr>
<td>Total = 10</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diagnosis (N = 10)</th>
<th>Trajectory (T) (N = 10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung cancer = 4 (40%)</td>
<td>Range: 3-18 days</td>
</tr>
<tr>
<td>Other cancer = 5 (50%)</td>
<td>Mean: 8 days</td>
</tr>
<tr>
<td>Other disease = 1 (10%)</td>
<td>Number of patients with T of 3-6 days: 6</td>
</tr>
<tr>
<td>Total = 10 (100%)</td>
<td>Number of patients with T of 8-18 days: 4</td>
</tr>
<tr>
<td></td>
<td>Total = 10</td>
</tr>
</tbody>
</table>
In every case, the family members expressed gratitude for the information supplied by the nurse investigator. Most stated that they had wondered what to expect during the dying process and expressed a desire to know.

**Respiratory Rate**

In order to examine the data collected on respiratory rate, the rates were divided into increments of five, beginning with one and ending with 40. The respiratory rates were grouped according to the check points at which they were collected by the investigator (admission check, check 1, check 2, and check 3). Respiratory rates were obtained for all ten subjects within 24 hours of admission (admission check), and also within 24 hours of clinical death (check 3). However, because of the difficulty in predicting the trajectories of the terminally ill patients, and due to job and personal commitments of the investigator, only seven of the subjects were observed at another time during the hospice stay (check 1), and of these seven, three subjects were observed at two other times (checks 1 and 2) before the final check within 24 hours of clinical death (check 3). In the interest of keeping the amount of data at a manageable level, the investigator made no attempt to observe the respiratory signs on a daily basis, or at set intervals.

At the admission check (N = 10), three subjects had a respiratory rate below 16 respirations per minute (11, 14, 14). The highest respiratory rate on admission was 26 respirations per minute, with the lowest rate at 11 respirations per minute. One subject had a respiratory rate
of 20. Four subjects' respirations fell in the 21 to 25 respirations-per-minute range, and two fell in the 26 to 30 respirations-per-minute range (see Table 2).

At check 1 (N = 7), four subjects had respiratory rates in the six to 10 respirations-per-minute range, and one subject fell in the 16 to 20 respirations-per-minute category. One subject had a respiratory rate of 22, and one subject's respiratory rate was measured at 26 respirations per minute.

At check 2 (N = 3), the respiratory rates for two subjects fell in the six to 10 respirations-per-minute category (10, 10), and the rate for one subject was four respirations per minute.

At check 3 (N = 10), within 24 hours of clinical death, the respirations-per-minute of one subject fell in the one to five respirations-per-minute range (5). No one had respiratory rates in the six to 10 respirations-per-minute category. In the 11 to 15 respirations-per-minute category, three subjects' respirations were 11, 13, and 14 respirations per minute, respectively. Two respiratory rates fell in the 16 to 20 respirations-per-minute category (19, 20); two respiratory rates fell in the 21 to 25 respirations-per-minute category (21, 24); and none fell in the 26 to 30 respirations-per-minute category. One subject's respiratory rate fell in the 31 to 35 respirations-per-minute grouping (32), and one fell into the 36 to 40 respirations-per-minute grouping (36).

Subjects 1, 2, and 3, who were observed a total of four times had long trajectories (over eight days), and showed a trend toward a
Table 2. Number of subjects demonstrating various respiratory rates at each observation.

<table>
<thead>
<tr>
<th>Observation Check</th>
<th>Respiration Per Minute</th>
<th>1-5</th>
<th>6-10</th>
<th>11-15</th>
<th>16-20</th>
<th>21-25</th>
<th>26-30</th>
<th>31-35</th>
<th>36-40</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admission (N = 10)</td>
<td></td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Check 1 (N = 7)</td>
<td></td>
<td>0</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Check 2 (N = 3)</td>
<td></td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Check 3 (N = 10)</td>
<td></td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
normal respiratory rate of 20 to 22 at the admission check. After three to eight days, all showed a dramatic crop in respiratory rate to eight and nine respirations per minute. The first two subjects then showed a slight increase in respiratory rate before demonstrating a dramatic increase in respiratory rate to 32 and 36 respirations per minute within 24 hours of death. The third subject slipped to a respiratory rate of four six day before death, but had a respiratory rate of 14 within 24 hours of death.

Subject 4, the 41-year-old male with lung cancer, was admitted with a respiratory rate of 24 respirations per minute 10 days before death. Six days before death, his respiratory rate was 22 respirations per minute, and he was observed with a respiratory rate of 24 within 24 hours of death. Only three observations were made of this subject.

Six subjects with short trajectories of five days or less in general showed a decrease in respiratory rate between the admission check and check 3. In one case, the subject was observed with a respiratory rate of 14 at the admission check, with a respiratory rate of 10 the next day, and then dropped to five respirations per minute within 24 hours of death. One subject was admitted with a respiratory rate of 26, had a respiratory rate of 26 two days later, on the day of death, and then showed a dramatic drop later that day to 19 respirations per minute. Subject 7 was admitted with a respiratory rate of 11, had a respiratory rate of 15 the next day, and then was observed with a respiratory rate of 11 within 24 hours of death, the third day.
Subject 8, who was observed only at the admission check and check 3, showed a slight decrease from the admit check of 23 respirations per minute to 21 four days later, within 24 hours of death. Subject 9 was admitted with a respiratory rate of 30, and then was observed with a respiratory rate of 20 within 24 hours of death. Subject 10 had a respiratory rate of 14 on admission, and a rate of 13 four days later within 24 hours of death. (See Table 3.)

Respiratory Signs Observed by the Investigator from Admission Check to Check 3 According to Subject

The narrative that follows describes, by subject, the respiratory signs observed by the investigator from the time of admission until clinical death. The sequence of respiratory changes are best described by subject.

The first subject was a 68-year-old female with a diagnosis of cancer of the pancreas with portal obstruction and ascites. Within 24 hours of her admission to the hospice unit, her respiratory rate was measured by the investigator as 22 respirations per minute. None of the respiratory signs listed on the instrument was observed to be present at that time. At check 1, on day three of her hospice stay, this subject was observed to have a cough, and breathing was more shallow than it had been two days previous. Her respirations at this time were observed at eight respirations per minute. This subject's trajectory was assessed to be rather slow, and although she actually was observed three times between check 1 and check 2, data were collected on day 12 of her hospice stay.
Table 3. Respiratory rate per minute by subject, admission check to check 3.

<table>
<thead>
<tr>
<th>Subject</th>
<th>On Admission</th>
<th>Check 1</th>
<th>Check 2</th>
<th>Check 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>22</td>
<td>8</td>
<td>10</td>
<td>36</td>
</tr>
<tr>
<td>2</td>
<td>22</td>
<td>9</td>
<td>10</td>
<td>32</td>
</tr>
<tr>
<td>3</td>
<td>20</td>
<td>8</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>4</td>
<td>24</td>
<td>22</td>
<td>--</td>
<td>24</td>
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<tr>
<td>5</td>
<td>14</td>
<td>10</td>
<td>--</td>
<td>5</td>
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<tr>
<td>6</td>
<td>26</td>
<td>26</td>
<td>--</td>
<td>19</td>
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<tr>
<td>7</td>
<td>11</td>
<td>15</td>
<td>--</td>
<td>11</td>
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<tr>
<td>8</td>
<td>23</td>
<td>--</td>
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<td>20</td>
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<td>10</td>
<td>14</td>
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<td>13</td>
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</table>
as a check 2 measurement. Respirations per minute were 10, and Cheyne-Stokes breathing was observed, with apnea of 15 seconds. However, over the next several days, this subject stabilized. Check 3 took place on day 17 at 200 hours. At this time, the subject exhibited shallow breathing, and respirations of 36 respirations per minute. No Cheyne-Stokes or apnea was noted. Clinical death came on day 18 in the early morning hours. (See Appendix E for chart detailing presence or absence of respiratory signs by subject.)

Subject number 2 was a 68-year-old male with a diagnosis of cancer of the lung, with cachexia, dehydration and weakness. Within 24 hours of admission to the hospice unit, his respiratory rate was observed to be 22 respirations per minute. This gentleman exhibited a cough at this time. At check 1, on day eight of his hospice stay, the subject's respirations per minute were nine, and he was observed to be gasping for breath. Check 2 came on day nine, since the subject's condition was thought to be declining rapidly. At 0800 on day nine, none of the respiratory signs on the instrument was observed, and the respiratory rate was 10 per minute. However, at 1050 that night, when the observer arrived just before the subject expired, hyperpnea was observed, and the respiratory rate was 32 per minute. Use of the accessory muscles was assumed since excavation of the supraclavicular fossae was noted.

The third subject was an 86-year-old female with cancer of the stomach. Within 24 hours of her admission to the hospice unit, her respiratory rate was measured at 20 respirations per minute, and none of the respiratory signs on the instrument was observed to be present.
On day six of her hospice stay, stertorous breathing was observed, along with a cough, and a respiratory rate per minute of eight. By day eight, the subject was exhibiting a cough, shallow breathing, and a decrease in stertorous breathing, together with apnea lasting 10 to 15 seconds. Other respiratory signs noted were a longer inspiratory phase and a shorter expiratory phase than normal. Respirations were four per minute, and death seemed imminent. However, this subject stabilized until day 14, when the respirations per minute were 14 and very shallow at 1800 hours. The subject died at 0600 hours on day 15.

Subject number 4 was a 41-year-old male with a diagnosis of cancer of the lung. Within 24 hours of admission to the hospice unit, his respirations were observed to be 24 per minute. Excavation of the supraclavicular fossae and recession of the intercostal spaces were observed to aid in breathing, as was the sign of purse-lip breathing, used intermittently; hyperpnea was also noted. At check 1, on day four, the respiratory rate was 22 per minute, and all the same signs as previously described were observed. No check 2 data were obtained. On day 10 at 1650 hours, check 3 was taken, and the subject exhibited the same signs observed on admission. He died on day 11 at 1100 hours.

Subject number 5 was an 81-year-old female with a diagnosis of sepsis, spine disease, congestive heart failure, ten-plus pathological fractures, and pulmonary embolism. Within 24 hours of admission, the subject's respiratory rate was 14 per minute, and no respiratory signs were observed. By day two, she was exhibiting stertorous breathing, Cheyne-Stokes breathing, and apnea of over 10 seconds. A prolonged
inspiration was noted, and the respiratory rate was 10 per minute. No check 2 was obtained. Check 3 took place on day four at 1830 hours. Respiratory rate was five, and apnea was observed to last from 10 to 30 seconds. This subject was reported by staff to have exhibited stertorous breathing until 1500 of that day, when she received atropine to quiet her noisy respirations. No stertorous breathing was noted at 1830 of the same day by the investigator. This subject died later that evening.

Subject number 6 was a 65-year-old male with a diagnosis of cancer of the lung with liver metastasis and chronic obstructive pulmonary disease of long standing. Within 24 hours of his admission, his respiratory rate was observed to be 26 per minute. He was exhibiting recession of his intercostal spaces, and was observed to have a long inspiratory phase of his respiratory cycle. By day three at 1400 check (check 2), this subject was observed with hyperpnea, as well as the recession of his intercostal spaces, and his respiratory rate per minute was still 26. Check 3 took place later that evening, as the subject's breathing changed, and was observed to be shallow with the respiratory rate at 19 per minute. No recession of the intercostal spaces was noted at this time. The subject died on day four in the early morning hours.

Subject number 7 was a male, age 86, with cancer of the larynx, and metastases to the lung and esophagus. Within 24 hours of admission, his respiratory rate was measured at 11 per minute. He was observed to be gasping at this time. On day two, check 1, Cheyne-Stokes respirations were observed, with 15 seconds of apnea. Respiratory rate was 15 per
minute. By check 3 on day three, respiratory rate was 11 per minute, and the subject was breathing shallowly. No Cheyne-Stokes or apnea was observed. He died on day four at 0600.

Subject number 8 was a 73-year-old male with a diagnosis of cancer of the colon, and aspiration pneumonia. Within 24 hours of admission to the hospice unit, his respiratory rate was observed at 23 per minute. No respiratory signs on the instrument were observed to be present on admission. On day five (check 2), this subject's respiratory rate was 21, and still no respiratory signs were observed. He died on day six at 0300.

Subject number 9 was a male of 83 with a diagnosis of cancer of the lung, with metastases. Within 24 hours of admission, his respiratory rate was 30, and he exhibited cough, stertorous breathing, and very shallow breathing. On day four at 0130 he was observed to be gasping and exhibiting stertorous breathing just prior to death. Respirations were 20 per minute.

The tenth subject was a 79-year-old male with a diagnosis of cancer of the prostrate gland. Within 24 hours of admission to the hospice unit, his respiratory rate was 14, and no respiratory signs in the instrument were observed to be present. On day five, at 1700 hours (check 3), his respiratory rate was 13, but no respiratory signs were observed. The subject died early the next morning.

Occurrence of Signs

The investigator observed for 11 respiratory signs traditionally thought to be associated with the process of dying in 10
terminally ill patients. Nine of the 11 signs of the tool were, in fact, noted by the investigator to be present in at least one subject. Neither nasal flaring nor stridor occurred in any of the subjects at any time. However, the additional signs of purse-lip breathing and recession of the intercostal spaces were observed. A narrative detailing the occurrence of the signs follows.

Cough was observed in four subjects. At the admission check, cough was observed in two subjects, both of whom had a diagnosis of lung cancer. However, neither subject exhibited a cough at check 3. In another subject, cough was observed at check 1, 14 days before the death, but at no other time. In a different subject, an 86-year-old female with cancer of the stomach, cough was observed both at check 1 (eight days before death), and at check 2 (six days before the death), where it occurred with stertorous breathing, shallow breathing, and apnea. While cough was present in two subjects at the admission check (three days before death, and eight days before death), and was noted in a third subject at check 1 (eight days before death), as well in a fourth subject at check 2 (six days before death), cough was not present in any subject within 24 hours of death.

Stertorous breathing was noted in three subjects. In an 86-year-old female with cancer of the stomach, stertorous breathing occurred with cough at check 1 (eight days before death). In an 83-year-old male subject with lung cancer, stertorous breathing appeared with shallow breathing and cough, occurring three days before death. In the same subject, stertorous breathing occurred with gasping at check 3. In an
81-year-old female with sepsis and congestive heart failure, stertorous breathing appeared with Cheyne-Stokes respirations and apnea at check 1, two days before death. In summary, stertorous breathing occurred as early as eight days before death, and was observed at six days before, at three days before death, and two days before death. Stertorous breathing appeared with a variety of other respiratory signs.

Hyperpnea was observed to be present in three subjects. In a 41-year-old male with lung cancer, hyperpnea appeared with the use of accessory muscles (excavation of the supraclavicular fossae), and with recession of the intercostal spaces and purse lip breathing at the admission check, 10 days before death. All signs mentioned above were observed in this subject at check 1, six days before death, and at check 3. One other subject, a 65-year-old male with lung cancer, also exhibited hyperpnea in association with the use of accessory muscles and recession of the intercostal spaces at check 1, on the day before his death. A third subject, a 68-year-old male, also with lung cancer, was observed with hyperpnea and use of accessory muscles at check 3, near the time of his death. In all three subjects, hyperpnea occurred with the use of accessory muscles. In addition, all subjects had a diagnosis of lung cancer.

Shallow breathing was noted in five subjects. In an 83-year-old male with lung cancer, shallow breathing was observed at the admission check, three days before death. The sign appeared with cough and stertorous breathing. Shallow breathing also occurred in a 68-year-old female with cancer of the pancreas, in association with apnea, stertorous
breathing and cough at check 1, 14 days before death, and at
check 3. In an 86-year-old female with cancer of the stomach, the sign
of shallow breathing was observed by itself at check 2 (six days before
death) and at check 3. Two other subjects exhibited shallow breathing at
check 3, a 65-year-old male with lung cancer, and an 86-year-old male
with cancer of the larynx, with metastases to the lung and esophagus.
The sign occurred by itself both times. Therefore, shallow breathing
occurred in four subjects within 24 hours of death, but it also oc­
curred 14 days and six days before death. Shallow breathing occurred
both by itself and with other signs.

Cheyne-Stokes' respirations appeared in three subjects. No
observations of Cheyne-Stokes respirations were made in any subject at
the admission check. At check 1, two days before death, Cheyne-Stokes
respirations occurred in an 81-year-old female with sepsis. Stertorous
breathing was observed with Cheyne-Stokes breathing in this subject at
check 1, and apnea was part of Cheyne-Stokes respirations. Cheyne-
Stokes respirations also appeared at check 1, the day before death, in an
86-year-old male with cancer of the larynx and metastases to the lung.
Apnea appeared as part of Cheyne-Stokes respirations. At check 2, six
days before death, Cheyne-Stokes respirations with apnea appeared in a
68-year-old female with cancer of the pancreas. Cheyne-Stokes respira-
tions were observed six days before death, two days before, and one day
before death. This sign was not observed within 24 hours of death in
any subject.
Gasping appeared in three subjects. This sign appeared by itself at the admission check, two days before death, in an 86-year-old male with cancer of the larynx with metastases to the lung and esophagus. The sign appeared alone at check 1, the day before death, in a 68-year-old male with lung cancer. Gasping also occurred at check 3 in an 83-year-old male with lung cancer, appearing with stertorous breathing. Thus, gasping appeared in two subjects with primary diagnoses of lung cancer, and in one subject with a secondary diagnosis of lung cancer. On two occasions, gasping was observed within 24 to 48 hours of death.

Apnea appeared in four subjects, none of whom exhibited the sign at the admission check. Apnea appeared as part of Cheyne-Stokes respirations and in association with stertorous breathing in an 81-year-old female with sepsis two days before her death. Apnea appeared by itself in this same subject at check 3. In an 86-year-old male with cancer of the larynx and esophageal and lung metastases, apnea was associated with Cheyne-Stokes respirations at check 1, the day before death. As part of Cheyne-Stokes respirations, apnea occurred in a 68-year-old female with cancer of the pancreas at check 2, six days before death. In an 86-year-old female with cancer of the stomach, apnea occurred at check 2, seven days before death, where it was not part of Cheyne-Stokes respirations, but was observed in association with shallow breathing, stertorous breathing, and cough. Thus, apnea did appear by itself, not as part of Cheyne-Stokes respirations, in a subject within 24 hours of death, where the previous day, apnea had been part of Cheyne-Stokes respirations.
respirations in this individual. Apnea appeared seven days before death, six days before, two days before death, and within 24 hours of death.

The use of accessory muscles was assumed by the observation of the excavation of the supraclavicular fossae in a 41-year-old male with lung cancer at the admission check, 10 days before death. This sign occurred with hyperpnea, recession of the intercostal spaces and purse-lip breathing. At check 1, six days before death, and check 3, all the signs mentioned above were seen together in this individual. In a 68-year-old male with lung cancer, the excavation of the supraclavicular fossae was observed. At this observation, hyperpnea occurred with the use of accessory muscles. Thus, in two of the four subjects with diagnoses of lung cancer, hyperpnea was associated with the use of accessory muscles. The use of accessory muscles was seen as early as 10 days before the death, at six days before the death, and within 24 hours of death.

Other respiratory signs observed, that were not part of the instrument, were recession of the intercostal spaces and purse-lip breathing. (See detailed explanation of recession of the intercostal spaces and purse-lip breathing in a 41-year-old male with lung cancer in the section on hyperpnea, or in the section on use of accessory muscles.) Recession of the intercostal spaces also occurred by itself in a 65-year-old male with lung cancer at the admission check, two days before death. At check 1, on the afternoon of his death, this subject was observed with recession of the intercostal spaces, in association
with hyperpnea. By check 3, three hours later, recession of the intercostal spaces was no longer seen. Recession of the intercostal spaces was observed ten days before death, as well as on the day of death. In one subject recession of the intercostal spaces was present within 24 hours of death, and then disappeared three hours later.

Summary

Data concerning the respiratory signs of the dying process observed in 10 subjects during the study were presented in a number of ways. Subjects' respiratory rates per minute were grouped into eight categories according to observation check, and also were displayed across time by subject. The respiratory signs observed by the investigator from the time of admission until clinical death were described, according to subject. In addition, the appearance of the respiratory signs in relation to the occurrence of clinical death was examined.
CHAPTER 5

DISCUSSION OF THE FINDINGS

In drawing conclusions about the data on respiratory signs of the terminally ill patient during the dying process, it may be seen that no unique pattern was observed to be associated with the dying process. However, certain trends were seen which indicate that the generally accepted ideas about respiratory signs observed in the dying may need to be revised.

Cough appeared on admission, check 1 and check 2, but not at check 3 in any subject. Therefore, it is possible that the centers responsible for initiating the cough reflex may be depressed in some patients within 24 hours of death.

Given that stertorous breathing occurred as early as eight days before death, and then disappeared in the subject, stertorous breathing did not seem to signal imminent death. Thus, the "death rattle" cannot be used as an indicator of imminent death.

Given that hyperpnea occurred in association with the use of accessory muscles in two out of four patients with lung cancer, it is possible that patients with lung cancer may exhibit these signs more often than patients with other cancers. Hyperpnea was observed as early as 10 days before death, and as late as the time of death. Thus hyperpnea occurs throughout the dying process, but it is not necessarily a reliable indicator of imminent death.
Given that shallow breathing occurred in four subjects within 24 hours of death, shallow breathing seems to indicate imminent death. However, shallow breathing also occurred 14 days before the death of one subject, and six days before the death in another subject. Thus, the generally accepted idea that shallow breathing heralds imminent death was not sustained in this study.

Given that Cheyne-Stokes respirations were observed six days before death, two days before death, and one day before death, nurses cannot interpret the sign of Cheyne-Stokes respirations to mean that the patient is within hours of death. The fact that Cheyne-Stokes respirations were not seen in any patient within 24 hours of death may mean that the respiratory centers are further impaired close to the death of the individual.

Gasp ing occurred in all of the three subjects with a primary or secondary diagnosis of lung cancer within two days of death. It is possible that gasping is associated with lung cancer, and is observed late in the dying process.

Apnea not only appeared as part of Cheyne-Stokes respirations but also appeared by itself at seven days before death. Thus, it could be concluded that apnea can appear alone, and does not necessarily mean imminent death of the patient.

The use of accessory muscles occurred as early as 10 days before death, and also within 24 hours of death. Therefore, the use of accessory muscles cannot be taken as a reliable sign of imminent death.
Recession of the intercostal spaces was present in a subject within 24 hours of death, and then stopped some six to eight hours before death. Thus, it could be concluded that air hunger might cease in some patients just before death.

Given that dramatic rises and drops in respiratory rate were observed occurring in the space of one day, or even hours, it might be concluded that dramatic changes herald death. In fact, the data show that some patients stabilize after a dramatic change, and live for some days before death occurs.

Given that one subject has a respiratory rate of four six days before death, we may conclude that low respiratory rate indicates imminent death. Given that two subjects had respiratory rates of over 30 respirations per minute within 24 hours of death, we might conclude that exceedingly high respiratory rates may indicate death within a few hours or days.

One subject exhibited stertorous breathing at check 3 with a respiratory rate of 20. The data suggest that respiratory rate can be normal, even when a patient is observed with the "death rattle" within 24 hours of death.

Within 24 hours of death, three respiratory rates were in the range considered normal (16 to 20 respirations per minute), three were 10 to 15 respirations per minute, one was five per minute or below, and three respiratory rates were 24 per minute or over. Respiratory rate seems to be scattered across the spectrum from very low
to very high, and it appears that no pattern exists with respect to respiratory rate within 24 hours of death.

Given that atropine and morphine sulfate were administered to some patients during the dying process and no record was kept by the investigator regarding time of administration in relation to time of observation, we might conclude that these drugs most probably did affect the data. However, the extent to which these drugs may have affected the data cannot be calculated at this time.

**Implications for Nursing Care**

The data from the study on respiratory signs of the dying process demonstrated need for revision of the generally accepted ideas about the dying process. In light of the data, nurses must conclude that no one pattern of respiratory signs is seen in every dying patient. Therefore, nurses must be very careful about what they tell family members. Nurses must not give families the erroneous idea that the patient with a respiratory rate of five per minute has only a few hours to live, or that because a patient shows apnea, Cheyne-Stokes respirations or stertorous breathing that he or she can be expected to die within hours. Even a dramatic change in respiratory rate can be benign in predicting imminent death. Since nurses frequently are confused about whether or not they are observing Cheyne-Stokes respirations, or only apnea, staff nurses should count respiratory rates in their dying patients for one full minute.
Once investigators establish that certain signs are associated with the dying process, nurses can then initiate models for teaching families of the terminally ill. Families can be taught not only what breathing patterns they may see during the dying process, but also the physical signs of other body systems such as the circulatory, gastrointestinal, and genitourinary systems. At that time, nurse investigators can focus on studying the effectiveness of this teaching in increasing families' sense of control, in decreasing their anxiety, and in promoting the resolution of grief after the death.

If it is found that families are indeed less anxious and experience an increased sense of control from knowing what physical signs they may expect during the dying process of a family member, then some terminally ill patients might choose to die at home rather than in the hospital. With a confident family that is aware of the physical signs of the dying process and their implications, harrowing trips to the emergency department with a moribund loved one might decrease. Ultimately, if families of terminally ill patients keep them home to die, health care costs might decrease, as hospitalization of the dying becomes less routine.

As more terminally ill patients die at home, the demand for community health nurses educated to care for the special physical and emotional needs of the dying patient and his family will increase. Home health agencies can offer community hospice care as part of their services, and inpatient hospice units can employ community health nurse specialists to care for the terminally ill and teach their families.
Ultimately, the area of teaching the physical signs that may be observed during the dying process may become a separate body of knowledge that could be included in nursing school curricula. Nursing students may thus learn what to expect before they confront their first dying patients. General duty nurses who experience death infrequently on their units, once knowledgeable about the physical signs of the dying process, might feel less isolated from their dying patients, and might offer teaching of the family members about what to expect as part of their routine care.

Recommendations for Further Study

The occurrence of certain respiratory signs during the dying process in the terminally ill patients in this study suggests that a new area has been opened to nurse researchers. More studies are needed to identify the signs of the dying process. Some recommendations for further study follow.

1. Given that none of the respiratory signs studied was present in all patients at check 3 (within 24 hours before death), will some signs occur more frequently closer to the death, i.e., at four hours, two hours, one hour, and less than one hour?

2. Given that all lung cancer patients in this study exhibited gasping, will terminally ill patients exhibit similar physical signs during the dying process irrespective of diagnosis?

3. Given that some subjects in this study received atropine and morphine sulphate, both of which affect respirations, will other signs be common to the dying process, or will respiratory rate
fall into a pattern if no drugs affecting respirations are administered?

4. Given that certain respiratory signs have been identified as associated with the dying process, what other physical signs might be associated (musculoskeletal signs, circulatory signs, gastrointestinal signs, genitourinary signs)?

5. Given that families are taught the physical signs of the dying process, will families receiving teaching be more likely to keep dying patients at home?

• Will families be less likely to visit the emergency department when death is imminent?
• Will families resolve their grief more appropriately?
• Will families express an increased feeling of control over the situation after the teaching?
• Will families express a decrease in anxiety after the teaching?

**Summary**

Although no patterns were observed to be associated with the dying process in the study, certain trends were seen in the data. The appearance of stertorous breathing, shallow breathing, Cheyne-Stokes respirations, or apnea in the terminally ill patient may not be taken as conclusive signs of imminent death. A dramatic change in respiratory rate, or a very low respiratory rate, may not indicate death within hours.
Based on the data gathered in the study, some revision of the generally accepted ideas about the dying process seems to be indicated. However, the physical signs of the dying process must be studied in greater depth before any definite conclusions can be reached. Studies utilizing anticipatory guidance in teaching physical signs of the dying process to families also must be undertaken. Moreover, studies concerning the reactions of family members after teaching must be initiated. When the conclusions of these future studies indicate the need for teaching families what to expect during the dying process, nurses will have found yet another opportunity to provide support and comfort to families of the terminally ill.
APPENDIX A

DATA COLLECTION FORM
## DATA COLLECTION FORM

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<tr>
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<th>Admission Date</th>
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APPENDIX B

UNIVERSITY OF ARIZONA HUMAN SUBJECTS APPROVAL
THE UNIVERSITY OF ARIZONA COLLEGE OF NURSING
MEMORANDUM

TO: Stephanie A. Foster
2708 E. Blanton Drive, Tucson 85716

FROM: Ada Sue Hinshaw, R.N., Ph.D. - Jan R. Atwood, R.N., Ph.D.
Director of Research - Chairman, Research Committee

DATE: July 12, 1982

RE: Human Subjects Review: Respiratory Signs and Symptoms of
Terminally Ill Persons During the Dying Process

Your project has been reviewed and approved as exempt from University review by the College of Nursing Ethical Review Sub-committee of the Research Committee, and the Director of Research. A consent form with subject signature is not required for projects exempt from full University review. Please use only a disclaimer format for subjects to read before giving their oral consent to the research. The Human Subjects Project Approval Form is filed in the office of the Director of Research, if you need access to it.

We wish you a valuable and stimulating experience with your research.

ASH:ss
1982
APPENDIX C

ST. MARY'S HUMAN SUBJECTS APPROVAL
May 14, 1982

Ms. Stephanie F. Foster
2708 East Blanton Drive
Tucson, Arizona 85716

Dear Ms. Foster:

At the May 14, 1982 meeting of the Human Subjects Committee, your request to collect data for your Masters' Thesis, "Respiratory Signs and Symptoms of Terminally Ill Persons During the Dying Process" at Hospice of St. Mary's, was unanimously approved.

This project may begin on May 17, 1982.

Sincerely,

Jay Goldman, M.D., Chairman
Human Subjects Committee

Gary L. Henderson, M.D.
Chief of Staff
APPENDIX D

PARTICIPANTS' CONSENT FORM
A study is being conducted at Hospice of St. Mary's involving patients on the inpatient unit. Patients of the Hospice program who are expected to live a limited time, and who volunteer, will be participants of the study.

The purpose of the study is to gain knowledge about the observable respiratory signs during the last days and hours of life. This information will help nurses to teach families the meaning of respiratory signs that they observe, and also what to expect during this time. It is hoped that this information, when given to family members, will help to decrease their anxiety and enable them to cope more effectively.

In order to obtain the information needed for this study, the nurse investigator will observe the respiratory status of the patient within 24 hours of admission to the Hospice unit, twice during the patient's stay, and at some time near the death of the patient. She will observe the breathing patterns that occur, and measure the respiratory rate. In addition, the nurse investigator will make herself available to support family members through this difficult period. She will present the opportunity to answer questions you, or other family members, may have about what they observe and explain the meaning of the observations.

If you choose to participate in this study, there will be no cost to you, nor will there be any monetary reimbursement. There are no known risks to the patient. The anticipated benefit of your participation in this study is the gaining of knowledge to help other families in your situation.

Participation is voluntary; you are free to not participate, and you are free to change your mind and withdraw at any time, even if you already have agreed to participate. Your choice to participate, not
participate, or withdraw, will not affect the care given to the patient or to your family. If you participate, any questions you have about the study will be answered.

All identifying information used in the study, such as the patient name, diagnoses, and other demographic data collected, will be kept confidential. This information will not be given to any third party. You will not be identified on the data collection form by name or descriptive information, and analysis of the results will refer only to a number, not a name. The information gained will be used only for research and educational purposes, although portions of the data may be published in professional literature at a later date.

I have read the above disclaimer, I understand what it says, and I agree to participate in this study.
APPENDIX E

PRESENCE OR ABSENCE OF RESPIRATORY SIGNS BY SUBJECT
### Presence or absence of respiratory signs by subject.

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<td>M</td>
<td>73</td>
<td>OCa</td>
<td>Ad 1 Ad 2 Ad 3</td>
<td>X</td>
<td>O</td>
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<td>9</td>
<td>M</td>
<td>83</td>
<td>LCa</td>
<td>Ad 1 Ad 2 Ad 3</td>
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<td>O</td>
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<tr>
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<td>79</td>
<td>OCa</td>
<td>Ad 1 Ad 2 Ad 3</td>
<td>X</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>

### Notes
- **S** = sex (M or F); **A** = age; **Dx** = diagnosis.
- **LCa** = lung cancer; **OCa** = other cancer; **Sep** = sepsis.
- **Ad** = admit check; **1** = check 1; **2** = check 2; **3** = check 3.
- **X** = sign present; **O** = sign absent; **Δ** = no observation made.
- **Respiratory Rate**
- **Cough**
- **Stertorous Breathing**
- **Hyperpnea**
- **Shallow Breath**
- **Cheyne-Stokes Breath**
- **Casing**
- **Apnea**
- **Muscles**
- **Other**
REFERENCES


