Knowledge Level And Teaching Practices Of Hospice Nurses Regarding Terminal Dehydration

Kristi Adams Acker

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KNOWLEDGE LEVEL AND TEACHING PRACTICES
OF HOSPICE NURSES REGARDING
TERMINAL DEHYDRATION

by
KRISTI ADAMS ACKER

A Thesis
Submitted in Partial Fulfillment of the Requirements
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Knowledge Level and Teaching Practices of Hospice Nurses Regarding Terminal Dehydration

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Abstract

A current controversy exists whether or not to continue aggressive hydration in the terminally ill patient. Emerging research has suggested that terminal dehydration can be a palliative treatment option in end-of-life care. The purpose of this descriptive study was to explore the teaching practices and knowledge level of hospice nurses regarding terminal dehydration. The Integrated Clinical Judgment Model (Gordon, Murphy, Candee, & Hiltunen, 1994) guided this study. A researcher-developed questionnaire, Teaching Practices of Hospice Nurses Regarding Terminal Dehydration, consisting of six questions asking to identify personal teaching practices regarding terminal dehydration, and a second researcher-developed questionnaire, Terminal Dehydration Knowledge Level Questionnaire, consisting of 10 Likert-type statements, were administered. A convenience sample consisting of 54 full-time registered nurses employed in an Alabama community-based hospice was selected. Descriptive statistics of frequencies and percentages were used to analyze the data. The findings of the study revealed that
hospice nurses are often asked by patients and family members to provide teaching regarding the issue of terminal dehydration. Also, the findings revealed that hospice nurses are knowledgeable regarding terminal dehydration and support previous research reflecting terminal dehydration as a means of palliative care. The education of patients, caregivers, and other members of the healthcare profession regarding terminal dehydration can improve the quality of life for the dying patient.
Dedication

This research is dedicated to my husband, Stan, and my daughters, Olivia and Abby-Francis. Stan, you have been a wonderful companion and friend to me during these last few months, just as always. Your willingness to take on more than your share has never wavered, and your encouragement has never ceased. God answered all of my prayers and more when he blessed my life with you. Olivia and Abby-Francis, my heart swells when I think of the love that you two bring to my life. You both have been the inspiration for me completing this program. Your smiles and hugs have gotten me through many troubled spots along the road. I love you, girls, more than life itself.

You are the only person in the world that was ever necessary to me.

- Nathaniel Hawthorne
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A special thanks to my dear mother, Sylvia Mills, for taking the name “Grandmother” to a whole new level. Thanks for your help with the children and all the “other” things that you do without asking. You are more than a mother, you are my best friend.

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Chapter I

The Research Problem

For the past 25 years there has been an emergence of health care professionals dedicated to caring for the dying patient. The care is referred to as palliative and/or hospice care. Palliative and hospice care can be defined as professional care responding to the unique needs of terminally ill patients by providing physical and emotional care (National Hospice Organization, 1996). Good symptom control is an essential component of quality care at the end of life. Although palliative care has offered terminal patients and their caregivers newfound hope during the end of life phase, there remains a widespread dissatisfaction in the United States regarding the care of patients facing end of life (National Institute of Health, 1997). The problems associated with the delivery of palliative care can often be attributed to medical professionals being poorly educated in symptom control in terminal patients (Kaye, 1993).
Terminal patients experience many of the same symptoms at the end of life. Weight loss, pain, dyspnea, and anorexia are among the most frequently seen symptoms in the dying patient. Over half of the terminal patients report pain as a major symptom, and 70% of hospice patients complain of dyspnea (National Institute of Health, 1997). The National Hospice Federation (1993) estimated that 40% of terminal patients also experience terminal dehydration prior to death. Sense the end of life is finally being recognized as an important phase of life, palliative care professionals must be encouraged to strengthen their individual knowledge base and gain a sense of empowerment when treating symptoms at the end of life.

Hospice patients primarily consist of those patients with a diagnosis of terminal cancer in which cure is no longer an option (Kaye, 1993). Among cancer, hospice patients may suffer from terminal diagnoses resulting from AIDS, Lou Gehrig’s disease, heart or lung disease, and other fatal conditions (National Hospice Organization, 1996). The American Cancer Society (1998) projected that 564,800 patients would die from cancer alone in 1998. Of the 564,800 mortality projection, 9,500 patients in the
state of Alabama have been estimated to succumb to cancer death (American Cancer Society, 1998). Many of these patients with terminal diagnoses will elect to remain in their home and die using a hospice or palliative care program to help with end-stage symptom control. In Alabama, there are 64 licensed hospices providing care for terminal patients (J. Prince, Director of Hospice Licensure and Certification, April 20, 1999). The number of operating hospices in Alabama demonstrates a clear indication that palliative care continues to be an important component in the overall health care environment.

The purpose of this study was to explore the knowledge levels and teaching practices of hospice nurses regarding the issue of terminal dehydration as it relates to palliative care symptom control in the dying patient. Understanding and identifying what the knowledge base of nurses is regarding the issue of terminal dehydration can guide future educational experiences in areas to better promote palliative care. Taking one issue, such as terminal dehydration, that is commonly reported as a symptom in the end of life, researching and reporting the findings can benefit clinical care by assessing the
knowledge of the palliative health care professionals providing the direct care. This knowledge can then be translated into other areas of health care by promoting interventions that can be effective in relieving distressing symptoms at the end of life.

Establishment of the Problem

Terminal dehydration is a common phenomenon experienced in terminally ill patients at end of life. Determining the knowledge and teaching practices of the health care professionals providing the direct care and symptom management of the dying patients needs to be addressed. Summarizing what the nurses know and teach the patients and caregivers regarding terminal dehydration can directly impact what future educational measures should be implemented to other health care professionals in order to improve and better understand symptom control at the end of life with the overall goal to improve the quality of palliative care.

Many of the issues surrounding palliative care can appeal to the moral, ethical, and legal dimensions of those providing the care. The literature suggests that the opinions surrounding the moral and ethical aspects of terminal dehydration are varied. Some physicians have
reported the ethical and moral obligation to provide artificial nutrition based on the patient-physician relationship (Siegler & Shiedermayer, 1987). In fact, many believe that terminal dehydration is morally and ethically wrong. Micetich, Steinecker, and Thomasma (1983) reported physicians argue that maintaining hydration in the dying patient shows a respect for living things. Also, Micetich et al. (1983) cited that health care professionals demonstrate a quality of care by providing ordinary means of medical treatment. The researchers also stated that providing hydration continues to support the bond established between practitioner and patient by “doing something” instead of standing by, no matter how ineffective the actions. Some health care professionals have viewed terminal dehydration as abandonment on behalf of the medical community, because terminal dehydration can be easily corrected by intravenous therapy and hyperalimentation. Fainsinger (1997) indicated the need to hydrate terminally ill patients who were in renal failure in order to detour adverse effects of opioid toxicity in the dying patient on analgesic medications for pain.

Moral and ethical issues surround terminal dehydration as well as legal matters, especially with the
debate surrounding passive euthanasia. Solomon et al. (1993) reported that 42% of the health care professionals agreed that when all other life supports have been discontinued, food and water should always be continued. This finding is based on the belief that food and water are not extraordinary means of treatment, but rather ordinary and essential.

On the other hand, literature suggests that hospice nurses consider intake cessation beneficial to the dying patient (Andrews & Levine, 1989; Dolan, 1983; Zerwekh, 1983). Joyce Zerwekh, a hospice nurse, gave her opinion regarding terminal dehydration by holding to the mandate "to comfort, always" (Zerwekh, 1983). Zerwekh stated that terminal dehydration reduced pulmonary, renal, and GI secretions which in turn relieved the dying patient's worrisome side effects. The side effects that Zerwekh (1983) reported decreasing with terminal dehydration included coughing and pulmonary congestion, sensations of "drowning" and choking by the dying patient, fewer catheterizations and bedpan usage, fewer patient manipulations because of less incontinence, and less complaints of nausea and vomiting. Zerwekh concluded that terminal dehydration was, in fact, beneficial to the
patient and painful symptoms were unlikely. In a more recent article, Zerwekh (1997) reported the physiology of the living differs greatly from that of a dying patient and that terminal dehydration is not cruel, but rather a palliative and compassionate decision regarding end-of-life choices.

Another view supporting terminal dehydration was documented by Printz (1989) which indicated that terminal dehydration produced an increased production of ketones, which in turn produces a substance with anesthetic effects that is believed to dull the consciousness of dying patients. This particular finding indicated that terminal dehydration was not only not necessary in the terminal patient, but considered a palliative treatment option. The perception of giving drink to the dying is engraved in most everyone’s mind as being an action of no consequence except to ease the suffering of death itself. But, as more literature and research arise, the state of dehydration in the dying is believed to be morally and ethically acceptable and in some cases even beneficial (Billings, 1985; Meares, 1994; Smith, 1995; Zerwekh, 1983). Miller and Meier (1998) state, "Terminal dehydration, accompanied by standard measures of palliative care, offers patients a
way to escape agonizing, incurable conditions that they consider worse than death, without requiring transformation of the law and medical ethics” (p. 559).

Illness severity has often been measured by caregivers by discerning how much intake the patient consumes (Doran, 1985). Therefore, patient and caregivers are also affected by the moral and ethical issues surrounding terminal dehydration. It has been reported that there is an unexpected trend noted in terminal patients; as intake is increased, so is the perception of thirst experienced by the patient (Burge, 1993).

McCann, Hall, and Groth-Juncker (1994) stated that patients experiencing terminal dehydration reported that receiving inadequate food and fluids did not cause them suffering, but in some patients eating to please the caregivers caused abdominal discomfort and nausea. The loss of appetite by the patient is a cause of anxiety and a source of conflict to the patient caregivers (Holden, 1991). Anorexia and intake cessation have been shown to be more of a concern to the caregiver than to the patient (Holden, 1991).
Significance to Nursing

Clinical practice. Nurse practitioners are essential in promoting healthy lifestyles and providing education to the public that will hopefully prevent illness and defer possible complications originating from a subsequent illness. Research is needed to assess the knowledge base of nurses providing care to patients in all settings. In this research study the investigator explored the body of knowledge from hospice nurses regarding terminal dehydration. The importance of measuring current knowledge is essential in determining the influence that nurses have on the care of the terminally ill patient. Another important aspect of this research study was to report findings from nurses experienced in the care of the terminally ill patient, so the knowledge and teaching practices could be shared with other members of the health care profession that may not be apt in the issues surrounding palliative care. Palliative care can be improved by empowering health care professionals, as well as caregivers, of measures which alleviate distressing symptoms in the terminally ill patient. Supporting and educating caregivers involved with end-of-life issues promote empowerment and a sense of accomplishment rather
than failure when death occurs for the patient (Kaye, 1993). Chadfield-Mohr and Byatt (1997) highlight an important issue while discussing the concept of terminal dehydration. Since many terminal patients are cared for outside of the hospice setting and tend to be exposed to more technical approaches, it is important that healthcare professionals share their knowledge regarding palliative care measures.

**Education.** Henkelman and Dalinis (1998) state the importance of assisting other members of the health care profession regarding palliative care to better enhance individuals personal comfort levels and knowledge levels surrounding the issues and protocols relating to terminal care. Henkelman and Dalinis (1998) feel that the fear of liability or professional reprimand would diminish if professionals had a knowledge base in palliative care and could feel comfortable in teaching patients and caregivers regarding the effects of the disease process. Fox (1996) responded to the topic of nurses providing education to terminally ill patients and their caregivers by revealing that nurses often feel ill-prepared to educate terminal patients and their caregivers because they perceive themselves as having a limited knowledge base regarding
the effects of the terminal process. With the knowledge base of hospice nurses in this study, guidelines can be established to provide future educational opportunities to those health care professionals impacting palliative care and symptom control. Knowing what is understood and what teaching practices are being shared with terminal patients and their families regarding terminal dehydration can also guide future educational topics in symptom management.

Theory. Elizabeth Fox (1996) gave a profound statement: "... Practitioners must have a sound clinical and moral knowledge on which to base their decisions. Just as ignorance of the law is no defense, so too is ignorance of clinical and/or ethical knowledge" (p. 43). The conceptual/theoretical framework, The Integrated Clinical Judgment Model (Gordon, Murphy, Candee, & Hiltunen, 1994), utilized in the current research contributes an alternative way to incorporate the generic nursing process. Using this model, nursing colleagues everywhere can adapt and be better applicable when confronting moral and ethical dilemmas. In today's environment, moral and ethical issues abound and theory is essential to the advance practice nurse. Theory should be well understood and followed to resolve ethical and moral
issues in a manner which benefits all persons affected by
the dilemma.

Research. Nurse clinicians in primary care must be
educated in research studies dealing with quality of life
in terminal patients. Clinicians must identify which
treatment therapies do not improve quality of life. In
some cases treatment therapies complicate the dying
process and hasten death. More attention is directed to
patients’ wishes and their own personal right to decide.
Patients often rely on health care providers for educated
information when trying to decide their course of
treatment. The role of a nurse practitioner in primary
care can be beneficial in educating patients on the
pathophysiology of terminal diseases and what treatment
options improve and promote their quality of life. The
current research study elicited the general knowledge
levels of nurses providing direct patient care to
terminally ill patients. Also, teaching practices of
hospice nurses were examined and reported based on
information given to the patients and their families
regarding the issue of terminal dehydration and the
effects on comfort in the dying.
Conceptual Framework

Meares (1997a) indicated that nurses are moral agents; therefore, they must have formal knowledge regarding ethical principles in order to justify decision on more than personal intuition. The Integrated Clinical Judgment Model (Gordon et al., 1994) was utilized in this study. A conceptual framework is defined as a set of abstract and general concepts and propositions that involve integration of the concepts into a meaningful configuration (Fawcett, 1995). Gordon et al. (1994) combined diagnostic-therapeutic reasoning with ethical reasoning to formulate their model as a modification to the generic nursing process. Their model is based on the assumption that “clinical judgment is a multidimensional concept and every act of clinical judgment in nursing has diagnostic, therapeutic, and ethical dimensions” (p. 59). Gordon et al. (1994) believe that ethical dilemmas occur during assessment, diagnosis, and treatment. Because all hospice patients are given a Patients Bill of Rights and should legally be made aware of their rights to formulate an advance directive, one can assume as the patient becomes less able to participate in his or her own care, ethical and moral issues could present that would
interfere with the patient’s own wishes. The Integrated Clinical Judgment Model (Gordon et al., 1994) accounts for both clinical and ethical judgments made by the nurse. As decisions regarding end-of-life care continue to be debated, this conceptual framework will prove useful for implementing nursing plans with ethical and moral claims.

Murphy (1986) reports that ethical dilemmas in clinical practice usually result from value conflicts among those involved with direct care. The Integrated Clinical Judgment Model incorporates the ethical reasoning with the generic nursing process. With the first step of the generic nursing process of Information Collection and Interpretation Gordon et al. (1994) integrate ethical reasoning involving parties, claims, and basis. The model defines parties as “an interested person or institution involved in a moral dilemma” (p. 62). Claims is defined as “a statement of what a party specifically wants or believes he or she is entitled to have” (p. 62). Moral basis is defined as “a valid moral argument that supports the claim as judged from the viewpoint of the individual making the claim” (p. 62).

The second aspect of the generic nursing process is problem identification. The Integrated Clinical Judgment
Model integrates the need for a definitive statement of the ethical dilemma. The third aspect, plan for problem solving, involves the ethical reasoning of the need to prioritize the claims and the need to develop an action plan. Moral action is integrated with the implementation of the plan part of the nursing process. The last aspect of the nursing process is evaluation. Gordon et al. (1994) integrate the moral evaluation as a summary of ethical reasoning. Terminally ill patients are increasingly being served in the home by members of hospice (Meares, 1997a). Hospice nurses need to be well versed on the ethical reasoning components of the Integrated Clinical Judgment Model to provide quality hospice care to these terminally ill patients.

Assumptions

The basic assumptions for this study were as follows:

1. Levels of knowledge regarding the effects of terminal dehydration by hospice nurses can be measured.

2. Hospice nurses include some teaching regarding terminal dehydration to the patients and/or caregivers when discussing the end-of-life process.
3. Nurses use diagnostic-therapeutic reasoning and ethical reasoning when providing care to terminally ill patients.

Purpose of the Study

Nurses who are providing palliative care to terminal patients experiencing terminal dehydration must be well informed on the advantages and disadvantages of providing hydration in the dying patient. Many patients and their caregivers seek the knowledge of the nurse providing the care when making decisions regarding the best management of distressing symptoms at the end of life. The impact that the nurses have on palliative care can directly affect what end-of-life decisions are made by physicians, patients, and their caregivers. Nurses in palliative care need to be versed on the effects of terminal dehydration and its impact on symptom management. The nurse, in order to fully inform the patient and/or caregiver, should be aware of the pathophysiology of end-stage disease processes and the possible complications associated with terminal dehydration. The role of a nurse practitioner in primary care can be beneficial in educating patients on the pathophysiology of terminal diseases and identifying treatment options which improve and promote their quality
of life. This research study elicits the general knowledge levels of nurses providing direct patient care to terminal patients regarding terminal dehydration. Also, teaching practices are examined and reported as to what information is being given to the patients and their caregivers regarding the issue of terminal dehydration and the effects on comfort in the dying.

Statement of the Problem

Do hospice nurses who, by their profession provide palliative care, have an adequate knowledge base regarding terminal dehydration and symptoms associated with issue? And what are the hospice nurses teaching the patients and/or caregivers regarding the issue? Many families request counsel in aiding with the decision regarding what measures promote quality of life in the end-stage disease processes. Knowledge of nurses providing care to these terminal patients needs to be assessed along with what teaching information is being given to the patient and/or families dealing with the decision regarding continuing aggressive hydration.
Research Questions

In this study two research questions were explored:

1. What are the knowledge levels of hospice nurses regarding the effects of terminal dehydration in the terminally ill patient?

2. What are hospice nurses teaching terminal patients and their caregivers regarding terminal dehydration?

Definition of Terms

For this study, the following terms were defined:

Knowledge levels: Theoretical: the familiarity and known information regarding a particular subject. Operational: For this study, known information was measured specifically by recording on a Likert scale by individual subjects related to known information on the effects of terminal dehydration and the comfort levels in dying patients. Questions reviewed the body systems and the impact of terminal dehydration on the systems. Knowledge levels were defined by the Terminal Dehydration Knowledge Level Questionnaire (TD-KLQ).

Teaching: Theoretical: the act of sharing knowledge and skills to other individuals. Operational: For the purpose of this study, the teaching content was collected by a questionnaire and was limited to the information
regarding terminal dehydration which is being given to patients and their families and how the information is conveyed. Teaching levels are defined by the Teaching Practices of Hospice Nurses Regarding Terminal Dehydration Questionnaire.

**Hospice nurses:** Theoretical: individuals dedicated to the care of the dying. Operational: For this research study, individuals working with terminally ill patients in a community-based hospice facility in Northern and Central Alabama and having been employed in the hospice for at least 6 months.

**Terminal dehydration:** Theoretical: a disorder of salt and water depletion that occurs in the last several days of life as the patient loses the desire or the ability to take in food and/or drink (Jackonen, 1997). Stein (1989) defines terminal as (a) occurring at or forming the end of a series, succession, or the like: closing or concluding, (b) occurring at or forming the end of life. Dehydration, according to Stein (1989), is to lose water or moisture from the body or tissue. Operational: Terminal dehydration, for this study, was defined as a fluid intake less than 500 ml/day arising in the last few days of life when a dying patient elects not to receive aggressive
hydration and is too weak or sick to take fluids of any substantial amount by mouth.

**Terminally ill patients:** Theoretical: Individuals who, because of their illness, are expected to die or have an illness for which there is no known cure. Thomas (1989) defines terminal as an illness that, because of its nature, can be expected to cause the patient to die, usually a chronic disease for which there is no known cure. Operational: For the purpose of this study, terminally ill patients were individuals admitted with a life expectancy of 6 months or less to a hospice where services are performed primarily in their homes. Comfort rather than curative measures were sought by these individuals. The majority of the patients had a terminal diagnosis of cancer, but others experienced terminal conditions from heart disease, lung disease, AIDS, and Alzheimer's disease.

**Caregivers:** Theoretical: the provision of watching over and acting responsible, the ability to have concern for another individual besides self. Operational: For the purpose of this study, caregivers were individuals assuming the responsibilities of providing 24-hour care for the terminal patient. The individuals included family
members or friends of the patient. The caregivers were individuals who communicated distressing symptoms experienced by the terminal patients to the other members of the palliative professionals. The caregivers were responsible for anticipating problems related to symptom control and interact with the palliative team along with the patient. The caregiver was also responsible for making decisions regarding end-of-life care when the patient was not physically or mentally able to do so.

Summary

With more than 2,000 hospices nationwide (National Hospice Organization, 1996) palliative care constitutes a major part of health care. Palliative care gives patients and their caregivers the ability to face death with dignity (Kaye, 1993). Improving palliative care will empower physicians, nurses, and others caring for terminally ill patients in making decisions regarding what measures promote comfort at the end of life. Establishing the knowledge of health care professionals regarding symptom management will serve as invaluable data in recognizing further teaching needs to be considered for those directly responsible for managing and teaching regarding end-stage symptom control. The Teaching
Practices of Hospice Nurses Regarding Terminal Dehydration and the Terminal Dehydration Knowledge Level Questionnaire were used to elicit the knowledge levels and teaching practices of hospice nurses directly providing palliative care to terminally ill patients.
Chapter II
Review of Literature

There have been several studies stating opinions surrounding terminal dehydration and the benefits to the dying patients. However, little direct research exists on the benefits of terminal dehydration due to feelings of invasion on dying patients and their families at this sensitive and emotional time (Meares, 1994). Many studies have addressed hydration and nutrition cessation, but little has been established regarding terminal dehydration and the benefits or consequences of the state. In a study by Meares (1997b), the primary caregivers of terminal patients who had died not receiving artificial nutrition/hydration were interviewed, and their narrative responses were studied. Meares sought to understand and report what intake cessation meant to the primary caregivers who had witnessed the death of their loved ones choosing not to be artificially fed.

Meares (1997b) used a qualitative phenomenological inquiry to explore the lived experiences of the primary
caregivers. The sample design was purposive in that the researcher selected a variety of caregiver-to-patient relationships represented in the study. The sample was taken from a single hospice in the northeastern region of the United States and consisted of English-speaking women. The women in the study had been the primary caregivers of terminally ill cancer patients who had elected not to receive aggressive hydration/nutrition. All of the patients had died at home within one year prior to the study. The age of the selected caregivers ranged from 40 to 75 years. Meares used a demographic sheet and a semiStructured interview guide reviewed by peers to elicit conversations from the sample. The interview guide utilized specific probes to keep the interview format focused and consistent. The interview lasted 60 to 90 minutes each and was audiotaped within the caregivers personal homes. The audiotapes were then transcribed verbatim and compared with the written text to ensure accuracy.

Van Manen’s (1990) method of isolating themes and essences was used to analyze the interview data. The researcher, through multiple readings, identified seven essential themes consistent with the interviews. The
researcher used a detailed analysis of single sentences and words and a grid to organize the data for analysis. Meares chose either an experienced hospice nurse or a qualitative researcher to code a total of six transcripts, which compared favorably to the researcher’s findings. The researcher also shared themes isolated from the data with three women from the sample. The women from the sample confirmed the themes which captured the essence of their personal experiences.

Meares (1997b) reported seven universal themes which emerged were as follows: Meaning of Food, Caregiver as Sustainer, Concurrent Losses, Personal Responses, Ceasing to Be, The Meaning Now, and Paradox. The first theme, Meaning of Food, ranged from food being very important to some to having very little importance to others. The majority of the sample discussed the physical body’s need for food in order to sustain life and the difficulty they had in accepting that dying patients no longer viewed food as valuable. The second theme was Caregiver as Sustainer. Most of the caregivers encouraged intake and sometimes pressured the patients to eat by nagging, pushing, or begging. Within this particular theme, the researcher noted that the caregivers overall did not think that the
patients suffered physically from not eating. The third theme related to Concurrent Losses resulted in personal pain for many of the caregivers. Because the dying patients became cachexic, some of the caregivers felt watching this transition of personal independence to dependence was the hardest aspect of intake cessation to accept.

The researcher's fourth theme, Personal Responses, was divided among those of the dying patients and the caregivers. The patients' responses were to eat to relieve the anxiety and concern of the caregivers and to please their caregivers. The caregivers' personal responses regarding intake cessation ranged from mild concern to anguish based on a number of variables, including strength of the interpersonal attachment, the level of acceptance of the impending death, and the degree of the responsibility assumed by the caregiver on providing intake for the patient. The caregivers stated that they would have benefitted had they received information about what to expect as their loved one's disease progressed and the need to have confirmation by other health care professionals about their decision in accepting the cessation of intake. The fifth theme, Ceasing to Be,
represented different meanings to the caregivers under study. Three caregivers felt that the patients whom they cared for “starved to death.” The sixth theme, Being Bereaved--The Meaning Now, indicated that some of the caregivers continued to have changes in their eating habits since caring for their particular patient. Lastly, Meares (1997b) found that Paradox as a theme spanned the entire experience. The most difficult paradox for the caregivers to accept was shifting from “eating is best” to “not eating is best.” The researcher concluded that the caregivers did not find intake cessation physically painful, but the experience was emotionally painful for the caregiver and the patient.

Meares’ (1997b) study was relative to the current study as it focused on terminal dehydration and the effects on the patient. The current researcher finds that patients and caregivers are still not fully aware of the advantages and disadvantages of intake cessation. Healthcare professionals are ambivalent in their beliefs regarding terminal dehydration, and the ethical considerations still play an important part in how they respond to the patients and caregivers seeking consultation about terminal dehydration.
There continues to be opposing views as to whether or not withholding artificial hydration and nutrition affects the overall comfort of terminally ill patient in the last few days of life. The focus among health care workers tends to deal with the legal and ethical ramifications concerning the decisions regarding continuing artificial hydration and nutrition for a terminally ill patient seeking palliative care only. It is still imperative to research and explore the clinical effects of choosing not to hydrate and artificially feed a patient who is dying in relation to comfort levels verbalized by the patient or observed by those people providing the care. The study by Mears (1997b) was similar to the current researcher’s study as both studies addressed the issue of artificial hydration in terminal patients.

In a study by McCann, Hall, and Groth-Juncker (1994), the researchers investigated the frequency of symptoms related to hunger and thirst in terminally ill patients and if the symptoms could be palliated without forced artificial nutrition and hydration. McCann et al. sought to evaluate if limiting food and hydration to only that requested by the patients seeking only palliative care had any adverse effects on the patient’s quality of
life. McCann et al. based their study on the hypothesis that lack of food and fluids sufficient to replace losses did not cause terminal patients to suffer or decrease their level of comfort as long as mouth care was provided and thirst was alleviated with sips of water. The definition of "level of comfort" used to measure patients' adaptation to terminal dehydration and anorexia was recorded from direct statements from the patients or by the patients' families or caregivers. "Comfortable" was recorded for a patient if physical and emotional discomfort was relieved with support from the patient's family, caregivers, and/or medications. "Some discomfort" was recorded if only partial symptoms were relieved and "much discomfort" was recorded if discomfort could not be relieved using the above measures. The patients were defined as terminally ill, meaning that they were certified by their primary physicians as having a life expectancy of 3 months or less.

McCann et al. (1994) used a prospective design study and sampled only patients who were mentally aware and competent. The sample design was convenient as patients were selected consecutively when they were admitted to the palliative care unit. The majority of the patients had a
diagnosis of cancer or stroke. The patients came to the palliative care unit located in Rochester, New York, from either the hospital or their homes. The study took place over the course of one year. The total sample (N = 32) met the specific guidelines based on the patient’s own personal wishes regarding CPR, artificial hydration and nutrition, and the use of antibiotics. The mean age of the patients was 74 years. Twenty-three percent of the sample consisted of women.

The palliative care team was comprised of a multidisciplinary team (MDT) including a nurse, physician, social worker, dietitian, recreational therapist, and a chaplain. The MDT members were the data collectors and recorded information from the patients directly; if the patient was unable to respond due to an acute confusional state, the family members or caregivers would reply based on observations.

Mouth care was consistent for all patients and was comprised of cleaning, using various swabs and keeping the oral mucous moist with ice chips, hard candy, and lubricants. Food was never forced but offered routinely. Narcotics were used to treat pain and relieve the symptoms related to shortness of breath. Patients would be asked
standard and consistent questions by the MDT regarding their sensations of hunger, thirst, and dry mouth. A form for data recording was completed on each patient several times a day. Food consumption and fluid ingestion were recorded as well as their effects on hunger, thirst, and overall comfort.

McCann et al. (1994) found that hunger was not reported in 63% of the subjects, 34% of the subjects presented with hunger sensations only initially, and 3% reported hunger until death. Thirst or dry mouth was present in 38% of the patients under study until death. Another 34% of the sample denied thirst or dry mouth, and 28% of the subjects reported the symptoms initially. In regard to the patient’s level of comfort, 84% of the subjects were recorded comfortable until their death and 13% experienced some discomfort. Due to an acute confusional state, 1% of the patients could not report. There was no report of “much discomfort.” The authors concluded that terminal patients experienced comfort despite not having intake capable of sustaining adequate nutrition and hydration. Also noted were instances where a patient would consume intake just to appease the family
and in turn suffer abdominal cramps and nausea which decreased the patient’s level of comfort.

McCann et al.’s (1994) study was relevant to the current researcher’s study as it focused on dehydration and the effects on the level of comfort for the terminally ill patient. There is still much debate as to what is futile medical care and what is basic humane care. This topic continues to pose important questions regarding hydration and artificial nutrition and the effects on quality of life for terminal patients. The nurse in advanced practice must continue to research to ensure that health professionals are seeking the overall goal of beneficence when caring for the terminally ill patients.

In a landmark study by Andrews and Levine (1989) the authors sought to examine and report the correlation of experience in hospice nurses who had observed terminal dehydration and their individual perceptions of the state of terminal dehydration. Because there have been little research and much debate regarding terminal dehydration and the effects on comfort in the dying patient, Andrews and Levine (1989) wanted to find out if hospice nurses who were observing this state of dehydration felt as though
being dehydrated caused an increase in pain and in turn caused greater suffering in the terminal patient.

Andrews and Levine (1989) hypothesized that hospice nurses who directly observe terminal dehydration have a more positive perception of the state of terminal dehydration than nurses who have not had the experience in observing terminal dehydration. The authors operationally defined patient as being someone who did not receive food or fluid for at least 3 days prior to death. Andrews and Levine (1989) used a correctional design and had a sample representing one registered nurse from each hospice in New Jersey and Pennsylvania for a total of 127 subjects. The researchers used mailed surveys to gather data. The questionnaire, developed by the researchers, was divided into two parts. The first section dealt solely with the independent variable, experience. The remaining section measured the dependent variable, perceptions. Ten questions were asked in the second section, and a Likert scale was used for the section which measured positive and negative perceptions. Scores had a possible range of 10 to 50. A score of 50 indicated a more positive perception regarding terminal dehydration. These data were analyzed
using the Statistical Package for Social Sciences (SPSS) as cited in the researchers’ study.

Andrews and Levine (1989) had a return rate of 75.6% (n = 96). In measuring the independent variable the researchers reported that 91% of the respondents had observed patients who died not receiving hydration. The researchers concluded that hospice nurses were not only experienced in the terminal process, but were an appropriate group to question regarding comfort levels in the terminally ill patient in a dehydrated state. Andrews and Levine (1989) reported that 71% of the respondents agreed that the incidence of nausea and vomiting was reduced with terminal dehydration, and 73% of the respondents agreed that dehydrated patients rarely complained of thirst. About half of the subjects perceived a relief from the sensation of choking and drowning by the dehydrated patients, and 53% agreed that dehydration was beneficial to the dying patient. The majority (85%) of the hospice nurses perceived IV hydration as unnecessary when the dying patient complained with the side effects of dry mouth. Andrews and Levine (1989) determined that respondents (82%) disagreed with the statement regarding dehydration as being painful. The researchers accepted the
directional hypothesis. Hospice nurses experienced with patients dying in a dehydrated state held a more positive perception of terminal dehydration than those nurses who had not shared in the experience of terminal dehydration ($p = .0015$).

Andrews and Levine (1989) concluded that overall hospice nurses with experience with terminal dehydration viewed the phenomenon as producing a beneficial state for the dying patient. These subjects reported a decrease in distressing symptoms including vomiting, choking, and the sensation of drowning. The most straightforward question concerned dehydration and pain, for which 82% of the disagreed that terminal dehydration increased pain and suffering in the dying patients.

The research study by Andrews and Levine (1989) was relevant to the current researcher’s study because it dealt with the experiences and perceptions of hospice nurses and the current researcher examined the knowledge base and teaching practices within the same population. Andrews and Levine (1989) felt that additional research was needed from other experienced nurses in other states. The sample in the current research consisted of hospice nurses in the state of Alabama.
In a similar study, Musgrave, Bartal, and Opstad (1996) conducted a pilot study to identify the attitudes of Israeli terminal patients, their caregivers, and health care professionals regarding hydration in the terminal patient. The pilot study addressed the attitudes and explored the involvement of the nurses, caregivers, and the patients themselves in the decision-making process regarding end-of-life care. A sample of convenience was utilized consisting of 33 (N = 33) terminal patients hospitalized in an adult oncology unit in Israel. Musgrave et al. used brief questions to elicit their data from the subjects. Caregivers and nurses were asked, "Were you involved in the decision to start the patient’s IV?" And patients were asked, "Were you involved in the decision to start the IV?" The subjects could either respond with a yes or no. The patients, caregivers, and nurses were then asked, "What is your attitude toward the IV?" The doctor was asked at the initial admission and every subsequent day until the patient died, or was transferred to another care facility, "What were the reasons for starting the IV?" and "What are the reasons for continuing the IV?" The questions were administered by the nurses caring for the patients and the nurses recorded the exact words of the
patients, caregivers, and doctors. The nurses also recorded their personal opinion regarding the questions. These data were categorized by two researchers who agreed completely as to which category to place the responses. Each response was either placed in the positive, negative, or neutral category. Positive responses included indications that the IV was beneficial. Negative responses reflected answers that indicated the IV was detrimental. The neutral category included all answers without any report of beneficial or detrimental effects of the IV therapy.

Musgrave et al. (1996) found that 3% of the patients were involved in the decision-making process as to whether or not to initiate IV therapy. The vast majority (61%) were not involved in the decision-making process. The remainder (36%) were unable to clarify the question due to altered mental status. Likewise, only 13% of the caregivers were involved in the decision-making process and 81% maintained no involvement. Of the nurses in the study, 33% reported involvement in the decision-making process, and 64% reported no involvement. Attitudes toward IV therapy ranked favorably for the use of IV therapy with the caregivers reporting 81% and the nurses reporting 71%
as positive responses regarding therapy. The patients responded positively in 21% of the respondents. In regard to patient responses, 70% were categorized as unknown because of altered mental status of the terminal patients. The doctors reported medications ranked as the primary reason IV therapy was initially started and maintained for the patients. Musgrave et al. (1996) indicated that the findings of this study were expected due to the Jewish culture and the principle of sanctity of life.

In the study by Musgrave et al. (1996) the researchers recognized that these data held a biased reflection since the results reflected the Jewish cultural beliefs only. It is important to note that in the Israeli culture the doctors are the only ones who initiate IV therapy and the doctor-nurse relationship is defined as superordinate-subordinate. Knowing this relationship, the results cannot be generalized to the American culture. Also, the sample size was small and the measurements were lessened due to the incomplete responses by the patients due to mental changes in the dying patients. The most important limitation is the inability to generalize this study due to cultural differences as indicated by the researchers.
The Musgrave et al. (1996) study was similar to the current research because the controversy surrounding terminal dehydration was identified and the focus was on terminal dehydration. The main difference was between the Israeli culture versus the American culture as the setting.

In another study assessing the attitudes of health care professionals in regard to end-of-life care, including decisions surrounding terminal dehydration, Solomon et al. (1993) explored the following questions: What do clinicians know regarding end-of-life care guidelines and what are their personal views about end-of-life care? The setting was five separate hospitals with locations in Massachusetts, Georgia, Washington, and California. The sample consisted of 687 physicians and 759 nurses. Among the physicians surveyed, 54% were in medical services, 25% were in surgical services, and 21% were house officers. Both physicians and nurses reported 26% of the patients could be considered terminal or critically ill. A self-completed questionnaire containing 123 questions covering four topics was utilized in this study. The questionnaire was reviewed by a panel of experts, and face validity was established after completion of a pilot
study. The topics of the questionnaire included knowledge and attitudes relating to law, medical ethics, and ethical guidelines for clinical practice; knowledge and adherence to institution guidelines on the use of life support; patient involvement in the decision making; and, lastly, perceived impediments to good decision making and quality care.

Solomon et al. (1993) reported 47% of the respondents, including 70% of the house officers, reported that they had acted against their conscience in providing care to the terminally ill. Four times as many respondents were concerned about overly burdensome treatment rather than undertreatment of the terminal patient. Differences in responses by professions were assessed through Kruskal-Wallis nonparametric one-way analysis of variance. All statistical analyses were performed using the SPSS. Most of the respondents (88%) reported awareness of guidelines surrounding care of the terminally ill. Many of the subjects reported they were uncertain regarding the laws and ethics of their own profession, specifically concerning artificial nutrition and hydration in the terminal patient. This study emphasized the importance of
clarity in terms of all health care professionals in regard to guidelines specific to end-of-life care issues.

This study by Solomon et al. (1993) was relevant to the current research because both studies sought to address the knowledge level of health care workers regarding the issue of terminal dehydration. The Solomon et al. study, unlike the current research, also focused on the legalities of end-of-life care.

In a prospective study, Vullo-Navich et al. (1998) sought to explore the specific symptoms of the terminal dehydrated patient and the degree of comfort and whether comfort levels decreased with increasing dehydration and/or abnormal serum sodium levels. Vullo-Navich et al. also examined the Billing's (1985) hypothesis that terminal dehydrated patients have normal serum sodium levels. The prospective study was set in an inpatient hospice unit within a Veterans Affairs Medical Center. The study took place over a 2-year time frame. The subjects (N = 31) were comprised of 30 men and one female. The mean age was 64 years. The subjects were noted with a cancer diagnosis which was proportional to the national statistics. Data were collected by trained nurses recording their observations of the commonly reported
symptoms associated with terminal hydration, such as nausea, vomiting, dry mouth, thirst, abdominal cramping, diarrhea, constipation, increased urine volume/pharyngeal secretions, shortness of breath/coughing, choking/drowning sensations, edema, ascites, death rattle, and the increased need for tracheal and nasogastric suctioning. The degree of distress and the degree of comfort were recorded by the nurse. The degree of distress was recorded utilizing a 4-point Likert scale ranging from 1 for extremely intense to 4 for no distress. The level of comfort also was scored on a 4-point Likert scale with 1 being uncomfortable and 4 being comfortable. The nurses tabulated individual daily scores ranging from 3 to 12. Blood levels also were drawn on 15 of the patients to assess for serum sodium levels. The data collection nurses were blinded to any of the lab reports on the patients.

Vullo-Navich et al. (1998) reported a perfect comfort score of 12 for 85% of the cases. The remaining 15% did not report comfort scores less than 5. Sixty-one percent of the patients observed met the definition of dehydration as defined in the study of having a intake of less than 500 ml/day for 2 consecutive days. The authors reported that patients with abnormal serum sodium levels were not
noted to exhibit more distressing symptoms. On the contrary, the patients with abnormal serum sodium levels had a mean score in the top third in regard to comfort levels. Vullo-Navich et al. (1998) reported that their hypothesis, there is no difference in comfort levels between the hydrated and dehydrated groups, was confirmed by the study results. The most commonly reported symptom was dry mouth, which can easily be relieved by local measures. The authors also supported the theory of Billings (1985) that terminally dehydrated patients maintain normal serum sodium levels until death. The authors reported 56% of the sodium levels were within normal ranges, excluding patients with renal and hepatic diseases. The study of Vullo-Navich et al. was limited in that the sample was a non-random selection and the nurses may have reported the findings based own personal bias.

The study by Vullo-Navich et al. (1998) identified the effects of terminal dehydration, as does the current research. The main difference between the two studies is that Vullo-Navich et al. assessed the level of comfort reported by terminal patients and the current researcher assessed the knowledge level of hospice nurses regarding
the effects of terminal dehydration on the quality of life.

In this chapter a review of the literature has been presented. Comparisons and contrast of the literature have also been made against the current research. In Chapter II, the study design and the methodology in selecting the sample, setting, and data analysis will be presented. Limitations of the current research will be addressed as well.
Chapter III

The Method

A notable reflection in palliative care is the tenet "To cure sometimes, to relieve often, and to comfort always." Advanced practice nurses have the ability to impact health care by conducting needed research and enlightening other healthcare professionals on ways to provide adequate control of distressing symptoms in the terminal patient.

This chapter will present the methodology used to answer the following questions:

1. What are the knowledge levels of hospice nurse regarding terminal dehydration?

2. What are the teaching practices of hospice nurses regarding terminal dehydration?

Design of the Study

The term descriptive research has been defined as research designed to predominantly describe rather than explain a phenomenon (Polit & Hungler, 1995). A
A descriptive study was utilized for this research. The descriptive study design was appropriate because the researcher chose to describe the knowledge levels and teaching practices of hospice nurses regarding terminal dehydration. There were no comparisons or correlations derived from this study and no manipulation of variables to warrant an experimental design.

Limitations

A limitation of this study was the dependence on assessing the knowledge levels and teaching practices of hospice nurses in a restricted area of the Southeast. The sample may not be generalized to the whole population of hospice nurses providing palliative care. Another limitation was failure to randomly select subjects. Background differences may exist among the subjects. A failure to utilize nurses outside the palliative care spectrum also was considered a limitation in that the subjects assessed were all familiar with palliative care.

Setting, Population, and Size

The setting for this research was selected hospices in the central and northern portions of Alabama. The hospices were selected according to willingness to
participate and the number of registered nurses employed. The geographic locations also influenced the selection of the hospices because the researcher visited all hospices on site in order to collect the data. The hospices were all licensed by the Alabama State Board of Health Division of Licensure and Certification. There were eight separate community-based hospices selected. The average caseload of the hospices ranged from 20 to 100 patients. The hospices on the average employed 10 full-time registered nurses (RNs).

The target population for this study was registered nurses licensed in the state of Alabama and who had worked full-time in the selected hospices for at least 6 months prior to participation in the study. The target sample size was 100 subjects. Polit and Hungler defines convenience sampling as using the most conveniently available subjects for use in a study (1995). A sample consisted of 54 practicing RNs from hospices in the central and northern portions of Alabama. This was a sample of convenience in that the sample was selected on accessibility to the researcher.
Methods of Data Collection

Techniques/instrumentation. The Demographic Survey was completed by the participants in the study (see Appendix A). The Demographic Survey assessed the age, sex, and race of the subjects as well as the number of years in practice as an RN and the number of years in practice as a hospice nurse. The survey also noted any additional certifications of the subjects and identified the type of degree of the subjects. A questionnaire developed by the researcher, the Terminal Dehydration Knowledge Level Questionnaire (TD-KLQ), was utilized to assess the knowledge base of hospice nurses regarding terminal dehydration (see Appendix B). The TD-KLQ consisted of nine questions directly assessing the subject’s knowledge of terminal dehydration. The TD-KLQ questionnaire assessed one personal perspective question in regard to terminal dehydration as a palliative treatment option. The questionnaire was reviewed by a panel of experts; therefore, face validity was established. The subjects' responses were recorded on a Likert scale, and data were analyzed using descriptive statistics. Teaching practices of hospice nurses regarding terminal dehydration were assessed by a separate questionnaire developed by the
researcher, Teaching Practices of Hospice Nurses Regarding Terminal Dehydration (see Appendix C). This questionnaire was comprised of six questions which assessed the percentage of patients requesting the nurse’s knowledge regarding terminal dehydration, the comfort of the subject in discussing terminal dehydration with the patient and/or caregivers, and the nurse’s involvement with other members of the palliative support team. The instrument also reported the percentages of verbal instructions provided by the subjects, the percentage of written materials distributed, and the manner in which written material was distributed. Data were collected and recorded by the researcher and analyzed using descriptive statistics. The questionnaire utilized for this study had assumed face validity since it was reviewed by a panel of experts in the research field.

Procedures

The rights of human subjects were protected in the conduction of this study. Approval for the study was granted by the Mississippi University for Women’s Committee on Use of Human Subjects in Experimentation (see Appendix D) before formal contact was made to the hospices
selected for the study. The researcher arranged with the selected hospice directors for a time when the nurses could be together so the overview of the research study and the importance of their participation in the study could be addressed in a semi-structured meeting (see Appendix E). The researcher then verbally explained the research problem and stated the purpose of the study. An informed consent was then distributed to the subjects, and the researcher emphasized that participation in the study was completely voluntary and that there were no penalties for electing not to participate (see Appendix F). The subjects were instructed that the information given on the questionnaire would remain confidential and that the current researcher would be the only individual viewing and recording the data. The subjects were advised that the instruments would not require a signature and the information would remain anonymous.

After the subjects electing to participate in the study completed the informed consent, the Demographic Survey, teaching instrument, and knowledge level instrument were distributed in the mentioned order, and verbal instructions were given regarding completion of the questionnaire. The entire data collection process lasted
approximately 15 minutes. The researcher remained present as all questionnaires were completed by the subjects and was available to answer any question regarding the instruments.

Methods of Data Analysis

Data analysis was performed utilizing descriptive statistics. Specifically, percentages and frequencies were reported for this study. Once data were collected, the researcher coded and analyzed all ordinal data, and statistical findings were reported. All questionnaires were evaluated separately to ensure that respondents met the eligibility requirements.
Chapter IV
The Findings

The purpose of this nonexperimental descriptive study was to explore the knowledge level of hospice nurses regarding terminal dehydration and to elicit the teaching practices of the hospice nurses regarding terminal dehydration. The following chapter presents the findings, including a description of the sample and the analysis of the data in relation to the two research questions.

Description of the Sample

Convenience sampling was used to select the subjects for the study. The population was hospice nurses from eight hospices within the central and northern portions of Alabama. The sample (N = 54) consisted of registered nurses with greater than 6 months hospice experience. Data were collected using three questionnaires. The first questionnaire, the Demographic Survey, gathered the demographic background of the participants. The second questionnaire, Teaching Practices of Hospice Nurses...
Regarding Terminal Dehydration, assessed the teaching practices of the participants and the third, Terminal Dehydration Knowledge Level Questionnaire (TD-KLQ), assessed the knowledge level of the participating hospice nurses.

The ages of the subjects ranged from 26 to 63 years with a mean age of 43.74 years. Data concerning age ranges are presented in Table 1.

Table 1

Summary of the Age Ranges of the Sample Using Frequencies and Percentages

<table>
<thead>
<tr>
<th>Age (Years)</th>
<th>( f^a )</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>26-35</td>
<td>8</td>
<td>14.8</td>
</tr>
<tr>
<td>36-45</td>
<td>26</td>
<td>48.2</td>
</tr>
<tr>
<td>46-55</td>
<td>17</td>
<td>31.5</td>
</tr>
<tr>
<td>55-63</td>
<td>3</td>
<td>5.5</td>
</tr>
</tbody>
</table>

\( N = 54. \)

Of the sample, 98% were female, while 2% were male. The ethnic origin of the subjects was 87% white and 13% black. Highest degree held was Bachelor of Science in
Nursing (50%), Associate Degree in Nursing (37%), Master of Science in Nursing (1.9%), and 11.1% reported other. The subjects who responded "other" indicated that they had received a diploma degree. A total of 20.4% of the subjects were certified hospice nurses. Additional certifications were reported by 16.7% of the subjects.

A majority of the respondents (51.9%) reported 10 to 25 years of experience as a registered nurse. Only 7 of the hospice nurses had less than 5 years experience. Findings related to nursing experience are presented in Table 2.

Table 2

<table>
<thead>
<tr>
<th>Years</th>
<th>f^a</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 5</td>
<td>7</td>
<td>13.0</td>
</tr>
<tr>
<td>5 to 10</td>
<td>13</td>
<td>24.1</td>
</tr>
<tr>
<td>10 to 25</td>
<td>28</td>
<td>51.9</td>
</tr>
<tr>
<td>&gt; 25</td>
<td>6</td>
<td>11.0</td>
</tr>
</tbody>
</table>

N = 54.
The registered nurses in the sample were fairly evenly divided as to amount of experience as a hospice nurse. The findings related to experience as a hospice nurse are shown in Table 3.

Table 3

Summary of Years of Experience as a Hospice Nurse Using Frequencies and Percentages

<table>
<thead>
<tr>
<th>Years</th>
<th>f</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 months to 2 years</td>
<td>18</td>
<td>33.3</td>
</tr>
<tr>
<td>2 to 5</td>
<td>19</td>
<td>35.2</td>
</tr>
<tr>
<td>&gt; 25</td>
<td>17</td>
<td>31.5</td>
</tr>
</tbody>
</table>

*N = 54.

Results of Data Analysis

Data were analyzed using descriptive statistics. Two research questions guided this study. The first research question asked what the teaching practices of hospice nurses were regarding the effects of terminal dehydration. The Teaching Practices of Hospice Nurses Regarding Terminal Dehydration Questionnaire consisted of six questions which allowed the subjects to check the answer
that best described their personal teaching practices. The second research question asked what is the knowledge level of hospice nurses regarding the symptoms often associated with terminal dehydration. The Terminal Dehydration Knowledge Level Questionnaire (TD-KLQ) consisted of 10 questions which the participants could respond using a 6-point Likert scale. The last question on the TD-KLQ asked the participants to relate, from a personal perspective, if terminal dehydration could be considered a palliative treatment option.

The first question that was asked in the Teaching Practices of Hospice Nurse Regarding Terminal Dehydration Questionnaire sought to find exactly what percentage of patients and/or family members requested teaching instructions regarding terminal dehydration and the effects on comfort. The participants could respond to the question by selecting 25%, 50%, 75%, or 100%. Analysis revealed that 14.8% of all subjects received teaching requests made by terminal patients and/or family members regarding terminal dehydration 100% of the time. Most (42.6%) reported such requests from 75% of patients and/or family members, and 24.1% reported teaching requests from 50% of patients and/or family members. Of the participants
surveyed, 18.5% indicated they receive teaching requests only 25% of the time.

The second question asked if the participants felt comfortable in discussing the advantages and/or disadvantages of terminal dehydration with the patients and/or family members. The participants could respond by indicating yes, no, or sometimes. Most (81.5%) indicated that they felt comfortable discussing terminal dehydration with patients and/or family members while 16.7% "sometimes" felt comfortable, and only 1.8% replied that they were not comfortable, discussing the effects of terminal dehydration.

The third question asked the subjects whether they solicit other members of the interdisciplinary team for support with teaching. Seventy-two point two percent answered that they do request other members of the interdisciplinary team, while 24.1% answered sometimes, and 3.7% answered no.

The fourth question asked what percentage of the teaching practices were done verbally. The participants could respond using the percentages 25%, 50%, 75%, or 100%. Over half (59.3%) indicated that 75% of their teaching practices regarding terminal dehydration were
The fifth question concerned the amount of written materials used for teaching. Again, the participants were asked to reply in percentages. Most (68.5%) indicated that written materials comprise 25% of their teaching practices, while 14.8% answered 50%, 13% answered 75%, and 3.7% answered 100%.

The final question sought to identify what type of teaching enhancements are being used to give to patients and/or family members when teaching regarding terminal dehydration. The choices were as follows: pamphlets, preprinted teaching sheets, books, and articles. The participants could check all that applied, and they could also indicate any other forms of teaching enhancements that were not indicated on the questionnaire. Seventy-nine point six percent of the subjects indicated that they used preprinted teaching sheets, 72.2% used articles, and 59.3% used pamphlets. Only 33.3% replied that they use books as teaching enhancements, while 9.3% of subjects replied that they use forms of teaching enhancements other than the mentioned methods. The Internet was indicated by one of the 9.3% as an alternative form of teaching enhancement.
The second research question used the TD-KLQ to explore the knowledge levels of hospice nurses regarding terminal dehydration. A total of 10 statements comprised the questionnaire (including one personal perspective question), and the subjects were asked to indicate whether they strongly disagreed, moderately disagreed, slightly disagreed, slightly agreed, moderately agreed, or strongly agreed with each statement. The responses of all subjects by statement are presented in Table 4.

More than half (63%) of the subjects strongly disagreed that terminal dehydration is painful. Of the subjects, 44.4% answered that terminal dehydration reduces the bouts of vomiting in the terminal patient. The question regarding if thirst can be managed without aggressive hydration was answered strongly agree by 57.5% of the subjects.

When asked if pulmonary secretions are decreased with terminal dehydration, 46.3% strongly agreed, while 31.5% moderately agreed. Terminal dehydration offers “analgesic” benefits was answered with 44.5% strongly agreeing, while 24.1% moderately agreed with the statement.
Table 4

Summary of the Terminal Dehydration Knowledge Level Questionnaire Using Frequencies and Percentages

<table>
<thead>
<tr>
<th>Statement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly Disagree</td>
<td>Moderately Disagree</td>
<td>Slightly Disagree</td>
<td>Slightly Agree</td>
<td>Moderately Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>1. Terminal dehydration is painful.</td>
<td>f 34</td>
<td>% 63.0</td>
<td>f 11</td>
<td>% 20.4</td>
<td>f 1</td>
<td>% 1.8</td>
</tr>
<tr>
<td>2. When a patient experiences terminal dehydration, there is a reduction in the bouts of vomiting.</td>
<td>f 1</td>
<td>% 1.8</td>
<td>f 3</td>
<td>% 5.6</td>
<td>f 7</td>
<td>% 13.0</td>
</tr>
<tr>
<td>3. Complaints of thirst in the dying patient can be managed without aggressive hydration.</td>
<td>f 2</td>
<td>% 3.7</td>
<td>f 1</td>
<td>% 1.8</td>
<td>f 1</td>
<td>% 1.8</td>
</tr>
<tr>
<td>4. Pulmonary secretions and congestion are decreased with terminal dehydration.</td>
<td>f 2</td>
<td>% 3.7</td>
<td>f 2</td>
<td>% 3.7</td>
<td>f 2</td>
<td>% 3.7</td>
</tr>
</tbody>
</table>

(table continues)
Table 4 (continued)

<table>
<thead>
<tr>
<th>Statement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Terminal dehydration offers &quot;analgesic&quot; benefits to the dying patient.</td>
<td>1</td>
<td>1.8</td>
<td>3</td>
<td>5.6</td>
<td>12</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>1.8</td>
<td>2</td>
<td>3.7</td>
<td>4</td>
<td>7.4</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>0.0</td>
<td>2</td>
<td>3.7</td>
<td>22</td>
<td>40.7</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>0.0</td>
<td>0</td>
<td>0.0</td>
<td>25</td>
<td>46.3</td>
</tr>
<tr>
<td>7. Terminal dehydration causes apathy and depression in the dying patient.</td>
<td>22</td>
<td>40.7</td>
<td>17</td>
<td>31.5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>9.3</td>
<td>5</td>
<td>9.3</td>
<td>2</td>
<td>3.7</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>5.6</td>
<td>3</td>
<td>5.6</td>
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<td>8. There is a difference between terminal dehydration vs. hypo/hyper natrean dehydration.</td>
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<td>3.7</td>
<td>6</td>
<td>11.1</td>
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<td>9.3</td>
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<td>38.9</td>
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Table 4 (continued)

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<td>9. Pharyngeal suction is</td>
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<td>25.9</td>
<td>24</td>
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Note. N = 54.
None of the subjects strongly disagreed that terminal dehydration can prove beneficial to the patient. The sixth statement asking if terminal dehydration can prove beneficial, 46.3% strongly agreed and 40.7% moderately agreed with the statement. When asked if terminal dehydration causes apathy and depression in the dying patient, 40.7% strongly disagreed, while 31.5% moderately disagreed.

Of the subjects, 38.9% moderately agreed that there is a difference between terminal dehydration versus hypernatremic/hyponatremic dehydration. Forty-eight percent strongly agreed that pharyngeal suction is decreased with patients experiencing terminal dehydration.

The last question was a personal perspective question asking if terminal dehydration should be considered a form of palliative treatment, 44.5% of the participants strongly agreed and 25.9% moderately agreed.

The sample as well as the data collection and analysis for this study have been presented. Descriptive statistics, specifically percentages and frequencies, have been reported. In Chapter V, outcomes of the findings will be presented, including discussion, conclusions, implications, and recommendations.
Chapter V
The Outcomes

The focus on palliative care has continued to emerge over the last two decades and greater attention is focused on measures that help improve quality of life to terminal patients when cure is no longer a viable option. Due to the many troublesome symptoms experienced by the terminal patient during the dying process, those professionals dedicated to palliative care must make every effort to ensure good symptom control for their terminal patients. Every effort must be made to help validate and educate other healthcare professionals regarding quality of life within the palliative care community. Therefore, by identifying the teaching practices and knowledge levels of hospice nurses regarding the symptom of terminal dehydration, more information regarding quality of life can be established and disseminated among other members of healthcare and the public.

The sample consisted of 54 registered nurses working full-time and residing in the state of Alabama. The
Integrated Clinical Judgment Model (Gordon et al., 1994) was used to guide this descriptive study. This chapter includes a discussion of the findings, conclusions, implications for nursing, as well as recommendations for future research.

Discussion of Findings

The sample consisted of 54 registered nurses employed by a hospice in the state of Alabama. The locations of the hospice facilities were in the central and northern portions of Alabama. The subjects' ages ranged from 26 to 63 years with a mean of 43.74 years. Eighty-seven percent of the subjects were white and 13% were black. Fifty percent of the subjects held a Bachelor of Science in Nursing degree. Of the participants, 20.4% were certified hospice nurses. The years of experience as a hospice nurse reported by the participants indicated 2 to 5 years for 32.5% and over 5 years for 31.5%.

This study sought to answer the following questions:

1. What are the teaching practices of hospice nurses regarding terminal dehydration.

2. What are the knowledge levels of hospice nurses regarding terminal dehydration?
The Teaching Practices of Hospice Nurses Regarding Terminal Dehydration questionnaire was utilized to identify hospice nurses' teaching practices in patients and/or family members regarding the issues surrounding terminal dehydration. Findings revealed 14.8% of the participants received requests regarding terminal dehydration instructions by the patient and/or family members 100% of the time, while most (42.6%) reported such requests from 75% of patients and/or family members. These findings were consistent with the findings reported by Meares' (1997b) indicating that patients and caregivers are not fully aware of the advantages and disadvantages of intake cessation and their need to seek healthcare professionals for consultations. Based on the current study and from previous research, it is evident that patients and/or family members are seeking counseling in making decisions surrounding end-of-life care. Requests from families may motivate teaching by the nurse regarding terminal hydration.

The second question asked the participants if they were comfortable discussing the effects of terminal dehydration. Eighty-one and five-tenths percent indicated that they did feel comfortable discussing the effects of
terminal dehydration. This finding did not support the research findings of Musgrave et al. (1996) reflecting the Israeli culture and the noninvolvement in end-of-life decision making reported by the nurses interviewed. From this study the participants not only were frequently consulted to discuss the effects of terminal dehydration (as indicated in Question 1), but the hospice nurses were comfortable in discussing the issue. This finding may indicate that hospice nurses in the current study felt comfortable in their personal knowledge level concerning the effects of terminal dehydration regardless of the limited information from outside resources on the advantages or disadvantages of terminal dehydration.

On the third question addressing if the participants solicited other members of the interdisciplinary team to support their teachings on terminal dehydration, 72.2% replied yes. This is supported by the National Hospice Organization (1996) definition of palliative care which involves not only the physical parameters of the patients, but also the spiritual aspects. Nurses in this hospice setting were part of a team consisting of chaplains, social workers, and volunteers and may have felt comfortable consulting colleagues regarding teaching.
The fourth question asking about the amount of teaching that is being done was verbal. Over half (59.3%) of the participants responded that 75% of their practice was verbal, and another 29.6% answered 100%. This was significant in that nurses are responsible for providing patients with the knowledge necessary to make informed consent as supported by the Integrated Clinical Judgment Model (Gordon et al., 1994). The findings in Question 4 may be reflective of the amount of comfort experienced by the hospice nurses surrounding terminal dehydration or it could reflect the limited research studies reporting the advantages or disadvantages of the issue.

Less than 10% of the nurses surveyed used methods other than books, articles, pamphlets, and preprinted teaching sheets for educating families. The Internet was the only alternative teaching enhancement noted by the subjects. Again, this may be associated with limited publishing regarding end-of-life care. It is interesting that the Internet was indicated as another form of teaching enhancement for the participants. This form of teaching enhancement may be a significant means of sharing information regarding end-of-life issues for the future.
When exploring the knowledge level of hospice nurses regarding terminal dehydration, the Terminal Dehydration Knowledge Level Questionnaire (TD-KLQ) was used. In the first question asking if terminal dehydration is painful, 63% of the participants strongly disagreed. This supported the findings of Printz (1989) indicating that with terminal dehydration an increased production of ketones are evident, therefore, producing anesthetic effects for the dying patient. This concurs with the current findings that hospice nurses do not view terminal dehydration as painful and inhumane treatment. These hospice nurses, the majority of whom had practiced as registered nurses for more than 10 years, may have determined from years of experience that terminal dehydration was not painful.

Over half (57.5%) of the participants answered that complaints of thirst experienced in the dying patient could be managed without aggressive hydration. This finding is congruent with the research of Andrews and Levine (1989) and McCann et al. (1994). McCann et al. reported that meticulous mouth care can alleviate thirst in terminal patients. Based on the current researcher’s findings, hospice nurses are not in support of administering hydration in order to alleviate the
distressing symptom of thirst. This finding in the current study may be related to the years of experience of this group of hospice nurses.

In Question 2 asking if terminal dehydration caused a reduction in the bouts of vomiting, 44.4% of the participants strongly agreed. The fourth question assessed the knowledge of hospice nurses regarding terminal dehydration and the reduction of pulmonary secretions and congestion. Less than half (46.3%) of the participants strongly agreed, but 31.5% responded that they moderately agreed with the statement. These findings support the research of Andrews and Levine (1989) and the findings of Smith (1995) and Zerwekh (1983). Based on the current findings, there does seem to be a considerable amount of knowledge on behalf of the hospice nurses that terminal dehydration decreases pulmonary secretions and congestion, along with decreasing the bouts of nausea and vomiting, therefore, alleviating the choking sensation and other worrisome symptoms often experienced in the dying.

In response to the fifth question asking if terminal dehydration offers "analgesic" benefits to the dying, 68.6% of the respondents either moderately or strongly agree that terminal dehydration does offer some analgesic
effects to the dying patient. This, too, was supported by the findings of Printz (1989). From the majority of hospice nurses responding that terminal dehydration is not painful (Question 1) and that terminal dehydration can provide analgesic effects, it is evident that the symptom of terminal dehydration can be considered helpful to those dying patients who are experiencing pain in the last stages of their illness. Several of the participants responded that they strongly agree (46.3%) or moderately agree (40.7%) that terminal dehydration can prove beneficial in the terminal patient. This has been supported by Billings (1985), Meares (1994), Smith (1995), and Zerwekh (1983).

In Question 7, the participants were asked to reply to the statement as to whether terminal dehydration caused apathy and depression in the dying patient. Of the respondents, 40.7% strongly disagreed with the statement. Based on this finding, the current researcher would conclude that terminal dehydration, for the most part, would not affect the mental aspects of the dying patient. This is not supported by the findings of Printz (1989), which indicate that patients experiencing terminal dehydration experience a dulling of their consciousness.
The participants responded to Question 8, asking if there was a difference between hypernatremia and hyponatremia and terminal dehydration, with more diversified answers. Only 33.3% strongly agreed with the statement. This does not fully support the findings by Billings (1985) indicating that terminal dehydration was a mixture of both hypernatremic and hyponatremic states. Based on the current findings, there appears to be less understanding of the pathophysiology associated with the symptom of terminal dehydration in this group of nurses. Since a majority of the nurses had an Associate of Science in Nursing or a Bachelor of Science in Nursing degree, they may not have been exposed to the advanced pathophysiological concepts related to dehydration which is usually taught at a graduate level.

On Question 9, 48.1% of the respondents strongly agreed that pharyngeal suctioning is decreased in patients with terminal dehydration. This also supports findings by Andrews and Levine (1989) and Zerwekh (1983). According to the current findings, terminal dehydration cannot only be beneficial by decreasing worrisome symptoms of pulmonary secretions, but also decreases the amount of suctioning that has to be performed in the last few days of life.
Decreasing the amount of suctioning needed can increase the comfort levels of patients and family members as well as decrease anxiety levels associated with pharyngeal suctioning.

The last statement sought to answer if terminal dehydration could be considered a palliative treatment option from the hospice nurses' personal view. Of the participants, 44.5% strongly agreed that terminal dehydration could be considered a palliative treatment option. This finding did not seem to be as significant as other findings supporting terminal dehydration as palliative treatment (Fox, 1996; Smith, 1995; Zerwekh, 1997). Based on the current findings, it is suggested that there still is not an overwhelming belief that terminal dehydration alone should be considered a palliative treatment option. For the most part, the respondents recognized, in many circumstances, that terminal dehydration can prove beneficial. This study continues to validate that there are no easy answers surrounding end-of-life issues. Just as other studies have indicated, terminal dehydration must be assessed according to the patient's wishes and comfort levels rather than standard protocol.
Conclusions

The current researcher derived, from analyzing the descriptive statistics, the overall responses of the hospice nurses surveyed were essentially supportive of studies that exist supporting terminal dehydration as a means of palliative treatment. Overall, data did not support the obligation to provide artificial hydration based on moral and ethical obligations on behalf of the healthcare provider. Due to the subjects not fully agreeing on any one statement completely, the health care professional dealing with the symptom of terminal dehydration should always use current knowledge and judgments regarding aiding the decision process with the patient and/or family member. The Integrated Clinical Judgment Model (Gordon et al., 1994) continues to demonstrate usefulness in guiding the decision-making process for nurses and other healthcare professionals dealing with moral and ethical issues surrounding the end of life.

Implications for Nursing

A number of implications for nursing were derived from the findings of this study. Primary among the
findings is that, as nurse practitioners, there must be a clear understanding of what factors impact the quality of life for the dying patient. Nurse practitioners are becoming a primary source of information for patients and the community. Nurse practitioners care for patients with a number of problems, but, as family nurse practitioners, care of some patients will often be related to comfort measures due to a terminal condition.

Education. Nurse practitioners must be knowledgeable and comfortable in providing educational guidance for terminal patients and their family members. Nurse practitioners must also individualize each plan of care for the terminal patient and assess the patient and the caregiver. Initially, it is important to identify the issues that are worrisome to the patient and/or caregiver and educate accordingly.

Another implication for nursing is the importance of sound clinical knowledge of the effects of symptoms experienced by patients at end of life and the need to possess sound moral knowledge as well. Nurse practitioners being knowledgeable regarding end-of-life issues may also impact healthcare by providing educational services to other nonpalliative healthcare professionals and the
community. Sharing knowledge regarding worrisome symptoms experienced at end of life can promote quality care for terminal patients, as well as define palliative care as a vital division within healthcare.

Practice. Nurse practitioners can develop within their practice teaching enhancements that review end-of-life issues and address measures to help with the decisions regarding quality of life. If the nurse practitioner is not knowledgeable on the issues in which the patient and/or family member is seeking guidance, then there must be a referral to a more informative source in order to fully provide care for the patient. Nurse practitioners must stay informed on the issues surrounding palliative care.

Research and theory. There must be further research conducted on issues surrounding palliative care and what measures can better improve quality of life for terminal patients. Nurse practitioners can establish different recommendations in order to facilitate research. As indicated in the current study, there are many articles regarding terminal dehydration, but little is documented by formal research. Research is the foundation from which nurses practice and is essential in allowing nurse
practitioners to provide the most comprehensive plan of care for the terminal patient. Theory must also reflect the care provided by the nurse practitioner. The conceptual framework, the Integrated Clinical Judgment Model (Gordon et al., 1994), could be incorporated within the educational in-service provided to other members of the healthcare team. The Integrated Clinical Judgment Model not only would be beneficial for the application in palliative care, but it also could be applicable in any situation that involves moral and ethical reasoning.

The results of this study may make the nurse practitioner more aware of the effects of terminal dehydration on the dying patients and the complexities associated with making the decision as to continue aggressive hydration or withhold hydration. Further research is needed to identify effects of other end-of-life issues on the dying patient.

Recommendations

Based on the findings of this study, the following recommendations were made for future research in nursing:
1. Replication of this study focusing on a larger geographic area with a larger sample to determine generality.

2. Conduction of further research to identify barriers and facilitators to the education of patients and families regarding end-of-life care.

3. Implementation of further research examining the benefits of written versus verbal educational practices on issues surrounding end of life.

4. Conduction of research to explore nurses' comfort levels with other issues surrounding end of life.


6. Implementation of further research exploring the knowledge level of caregivers regarding terminal dehydration.

7. Conduction of further research to explore the perceptions of terminal patients and their caregivers on the issue of terminal dehydration.
REFERENCES
References


APPENDIX A

DEMOGRAPHIC SURVEY
Demographic Survey

1. How old are you?__________

2. What is your sex?
   _____ Female
   _____ Male

3. What is your race?
   _____ Black
   _____ White
   _____ Other (please specify):__________________________

4. How many years as an RN?
   _____ Less than 5 years
   _____ 5 to 10 years
   _____ 10 to 25 years
   _____ Over 25 years

5. Highest degree held
   _____ A.D.N.
   _____ B.S.N.
   _____ M.S.N.
   _____ Other (please specify):__________________________

6. Are you a certified hospice nurse?
   _____ Yes
   _____ No

7. Do you have any additional certifications?
   _____ Yes
   _____ No

   If so, please specify:_____________________________________

8. How many years have you been a hospice nurse?
   _____ Less than 6 months
   _____ 6 months to 2 years
   _____ 2 years to 5 years
   _____ Over 5 years
APPENDIX B

TERMINAL DEHYDRATION KNOWLEDGE LEVEL QUESTIONNAIRE
Terminal Dehydration Knowledge
Level Questionnaire

The following questions contain general information related to terminal dehydration. Please circle one number for each question with the number (1) indicating that you strongly disagree and the number (6) that you strongly agree.

1 = Strongly disagree  4 = Slightly agree
2 = Moderately disagree  5 = Moderately agree
3 = Slightly disagree  6 = Strongly agree

1. Terminal dehydration is painful.
   1  2  3  4  5  6

2. When a patient experiences terminal dehydration, there is a reduction in the bouts of vomiting.
   1  2  3  4  5  6

3. Complaints of thirst in the dying patient can be managed without aggressive hydration.
   1  2  3  4  5  6

4. Pulmonary secretions and congestion are decreased with terminal dehydration.
   1  2  3  4  5  6

5. Terminal dehydration offers "analgesic" benefits to the dying patient.
   1  2  3  4  5  6

6. Terminal dehydration can prove beneficial to the dying patient.
   1  2  3  4  5  6

7. Terminal dehydration causes apathy and depression in the dying patient.
   1  2  3  4  5  6

8. There is a difference between terminal dehydration and hyponatremic/hypernatremic dehydration.
   1  2  3  4  5  6

9. Pharyngeal suction is decreased with patients experiencing terminal dehydration.
   1  2  3  4  5  6

Personal Perspective: Terminal dehydration can be considered palliative treatment.
   1  2  3  4  5  6
APPENDIX C

TEACHING PRACTICES OF HOSPICE NURSES REGARDING TERMINAL DEHYDRATION
Teaching Practices of Hospice Nurses
Regarding Terminal Dehydration

1. Approximately what percentage of patients and/or family members request your knowledge regarding dehydration and its effects on comfort?
   _____ 25%
   _____ 50%
   _____ 75%
   _____ 100%

2. Do you feel comfortable discussing the advantages and/or disadvantages of terminal dehydration with your patients and/or family members?
   _____ Yes
   _____ No
   _____ Sometimes

3. Do you solicit other members of the interdisciplinary team to support your teachings regarding terminal dehydration that were given to the patient and/or family members?
   _____ Yes
   _____ No
   _____ Sometimes

4. Approximately what percentage of your teaching practices are conducted verbally?
   _____ 25%
   _____ 50%
   _____ 75%
   _____ 100%

5. Approximately what percentage of your teaching practices are in written form?
   _____ 25%
   _____ 50%
   _____ 75%
   _____ 100%

6. If written materials are given to patients and/or family members as teaching enhancements, what form do they take? (Check all that apply)
   _____ Pamphlets
   _____ Preprinted teaching sheets
   _____ Books
   _____ Articles
   _____ Other (please specify):_________________________________________________
APPENDIX D

APPROVAL OF THE COMMITTEE ON USE OF HUMAN SUBJECTS IN EXPERIMENTATION OF MISSISSIPPI UNIVERSITY FOR WOMEN
March 22, 1999

Ms. Kristi Adams Acker  
c/o Graduate Program in Nursing  
Campus

Dear Ms. Acker:

I am pleased to inform you that the members of the Committee on Human Subjects in Experimentation have approved your proposed research as submitted.

I wish you much success in your research.

Sincerely,

Susan Kupisch, Ph.D.  
Vice President for Academic Affairs

SK: wr

cc: Mr. Jim Davidson  
    Dr. Mary Pat Curtis  
    Ms. Melinda Rush

Where Excellence is a Tradition
APPENDIX E

AGENCY CONSENT
Dear Hospice Director,

As a graduate student at the Mississippi University for Women in Columbus, Mississippi, I am conducting research in partial fulfillment of my degree requirements. My research proposes to explore the knowledge levels and teaching practices of hospice nurses regarding terminal dehydration.

I am selecting hospices in the state of Alabama to elicit data for my research. The subjects being asked to participate are registered nurses employed for at least 6 months in a community-based hospice. Therefore, I am requesting permission to implement my research within your facility. Implementation of the study involves on-site distribution and collection of three brief questionnaires to be completed by the hospice nurses who are willing to participate.

The questionnaires explore the nurse’s teaching practices and knowledge levels regarding terminal dehydration. Also, a brief demographic survey will be taken. The combined questionnaires should require no more than 15 to 20 minutes to complete.

I plan to start my data collection in mid-March 1999. To facilitate your response, this letter may be signed to indicate your permission for the study to be implemented within your facility. A self-addressed, stamped envelope is enclosed for your convenience. I look forward to your reply. If you have any questions, please call me at home at (205) 339-9987. Thank you for your consideration of my research.

Sincerely,

Kristi Adams Acker, RN, OCN, CRNH
Graduate Student

Date: ____________________ Signed: ____________________
APPENDIX F

CONSENT OF PARTICIPANT
Dear Colleague,

As a graduate student in nursing at the Mississippi University for Women in Columbus, Mississippi, I am conducting research in partial fulfillment of my degree requirements. The purpose of my research is to explore knowledge levels and teaching practices of hospice nurses regarding terminal dehydration. The data needed for this research can be collected by the use of two brief questionnaires which should take approximately 20 minutes to complete.

Terminal dehydration in the dying patient continues to be a debated issue. Many families request counsel in aiding with the decision regarding what measures promote quality of life in the end-stage disease processes. Knowledge of the nurses providing the care to these terminal patients needs to be assessed along with what teaching information is being given to the patient and/or families dealing with the decision regarding continuing aggressive hydration.

Your participation is completely voluntary, and there are no penalties if you choose not to participate. Your individual answers are completely confidential and anonymous, as the questionnaires will only be identified by a code. If you choose to participate in the research study, you will contribute valuable information to health care by informing what information is being given to terminal patients and their caregivers regarding terminal dehydration, but, most importantly, you will give insight on how these patients and caregivers reach their decisions regarding quality of life in the end-stage disease process. Your participation would be greatly appreciated. This study was approved by the Committee on Use of Human Subjects in Experimentation of Mississippi University for Women to meet the ethical requirements for research. The following is the informed consent that you will need to sign and date if you choose to participate in this research study.

I give my permission to participate in the research study that Kristi Acker, RN, OCN, CRNH, will be conducting on knowledge levels and teaching practices of hospice nurses regarding terminal dehydration. I understand that my participation is voluntary and will not have any bearing on my employment status regardless of my decision to participate. I have been given a verbal description of this research study, and I have no further questions regarding the study. I understand that no names will be depicted on the questionnaire, and the researcher will be the only individual accessing the data collection forms. I grant permission to Kristi A. Acker, RN, CRNH, OCN, to include my responses to the questionnaire in her research study.

Date: _______________________  
Signature of Participant

_________________________________  
Signature of Witness