

OPINIONS OF REGISTERED DIETITIANS ON  
THE WITHHOLDING AND WITHDRAWING OF  
FOOD AND FLUID IN THE  
TERMINALLY ILL

by

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Committee Chairman: Dr. S. J. Ritchey

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## [ABSTRACT]

This study was conducted to investigate the opinions of dietitians regarding the withholding and withdrawing of nutritional support in terminally ill patients. In addition, the role of the dietitian in feeding the terminally ill individual was researched.

A mailed questionnaire was sent to 414 registered dietitians employed by the Marriott Corporation with at least one year of clinical experience. Of the 414 deliverable questionnaires, 284 [69%] were returned, and the results were tabulated. Data analysis included frequency distribution.

Results indicated that the majority of the dietitians were female younger than 40 years of age with at least a Bachelor of Science degree and were married. Dietitians with experience with advance directives and living wills were more likely to agree that the terminally ill individual and not the physician nor family member had the right to make the decisions regarding his or her medical treatment. There were no statistical differences when broken down according to the different variables.

Because most dietitians have not had any formal training in ethics, education for dietitians needs to focus on ethics skills to help dietitians to effectively deal with the challenges facing dietitians pertaining to feeding the terminally ill individual.

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## TABLE OF CONTENTS

### CHAPTER 1:

|                           |   |
|---------------------------|---|
| INTRODUCTION.....         | 1 |
| STATEMENT OF PURPOSE..... | 6 |
| HYPOTHESIS.....           | 6 |
| DEFINITION OF TERMS.....  | 7 |

### CHAPTER 2:

|                            |    |
|----------------------------|----|
| REVIEW OF LITERATURE.....  | 9  |
| HISTORICAL BACKGROUND..... | 16 |

### CHAPTER 3:

|                      |    |
|----------------------|----|
| METHODOLOGY.....     | 48 |
| INSTRUMENTATION..... | 48 |
| DATA ANALYSIS.....   | 50 |

### CHAPTER 4:

|                                 |    |
|---------------------------------|----|
| RESULTS.....                    | 51 |
| DESCRIPTION OF RESPONDENTS..... | 51 |
| DISCUSSION.....                 | 54 |

### CHAPTER 5:

|                 |    |
|-----------------|----|
| CONCLUSION..... | 60 |
| REFERENCES..... | 65 |
| APPENDICES..... | 70 |
| VITA.....       | 78 |

## LIST OF TABLES

### TABLE

|    |   |    |
|----|---|----|
| 1: | General considerations regarding nutrition care for the terminally ill adult          | 10 |
| 2: | Considerations for examining the efficacy of providing aggressive nutrition support   | 11 |
| 3: | Considerations for examining the efficacy of withholding aggressive nutrition support | 14 |
| A: | Demographic characteristics of respondents  | 53 |
| B: | Percentage of respondents according to age  | 57 |
| C: | Percentage of respondents according to degree   | 58 |
| D: | Percentage of respondents according to marital status                                 | 59 |

## Chapter 1

### Introduction

The terminally ill individual has a right to be a dominant force in selecting which level of treatment and care he or she receives [King & Maillet, 1992]. The position of the American Dietetic Association is that the Registered Dietitian should play an active role in establishing the criteria used for feeding the terminally ill patient within the practice setting and cooperate with the medical team in making recommendations on each case [King & Maillet, 1992]. Appropriate, comprehensive, yet compassionate, treatment of the terminally ill patient by the health care team is difficult and requires that the medical team be especially sensitive to the patient's physical and emotional needs [Printz, 1992]. As part of the health care team, the dietitian has an obligation to assist in meeting the physiological and psychological needs and desires of each patient on an individual basis, and for initiating, implementing, and evaluating individualized nutrition care plans for all terminally ill patients [Wade & Jain, 1984]. Further, the dietitian must respect life, and the respectability and rights of all individuals, and assist the medical team in furnishing relief from discomfort [King & Maillet, 1992].

Each patient approaches that conventional, universal end called death with very individual religious, philosophical, and personal attitudes and values [King & Maillet, 1992]. Pain and suffering may be regarded as a



significant means of personal growth or a religious experience; for some patients, life is of inestimable significance, no matter how intolerable and lacking in quality [King & Maillet, 1992].

According to the medical and legal professions, death is generally defined as "neurological brain death" [Maillet, 1995]; however, given religious principles, some individuals and specific groups do not accept the neurological criterion as the definition of death [King & Maillet, 1992]. It is the responsibility of the clinical dietitian to furnish a combination of emotional support and technical nutrition recommendations on how to best accomplish each patient's goals within legal parameters [Maillet, 1995]. By facilitating good nutritional health, the dietitian can add to the comfort of the patient for as long as possible [Wade & Jain, 1984].

Among the most frequently cited fears people have with respect to death is the anguish of emotional or physical desertion that the terminally ill often experience [King & Maillet, 1992]. Patients always have the choice and privilege of changing their minds about what health care they receive as life circumstances change. The dietitian must remain emotionally supportive if the patient decides to reject all forms of nutrition support [Maillet, 1995]. If a patient refuses food, dietitians should not construe this as a sign of personal or professional failure [King & Maillet, 1992].

Self-determination - the right of an individual to decide his or her own

destiny by accepting or rejecting offered care - is one of the most basic precepts of medical ethics and law [La Puma, Orentlicher, & Moss, 1991]. The Patient Self Determination Act took effect on December 1, 1991 and requires all Medicare/Medicaid health care providers to inform patients of their right to prepare advance directives and to refuse treatments. The crucial ethical responsibility is to ensure that the patient, not the family or institution, decides about his or her own medical treatments [Maillet, 1995]. Respect for the patient's right to self-determination may result in a conflict with the dietitian's own ethical value system [La Puma, Orentlicher, & Moss, 1991]. Some dietitians believe all patients need nutritional support; therefore, a patient's informed decision to reject nutritional support might go against an individual dietitian's personal sense of professional responsibility [King & Maillet, 1992].

Respect for, and consideration of the patient's informed preference for the level of nutritional support is important [King & Maillet, 1992]. The "benefit-burden" test has acquired some legal acceptance with the courts [Dresser & Boisubin, 1985; Lynn & Childress, 1983]. Under this test, therapy should be continued, at least for an incompetent patient who has left no advance directive, if the benefits to the individual outweigh the burdens [Dresser & Boisubin, 1985; Lynn & Childress, 1983]. There is a growing body of expert views that there are examples in which feeding by any means becomes an enormous and discouraging venture [Dresser & Boisubin, 1985; Lynn &

Childress, 1983]. Sometimes the burden of pain and discomfort associated with offering nutritional support significantly outweighs the benefits [Dresser & Boisaubin, 1983; Lynn & Childress, 1983]. For the individual patient with severe medical degeneration, nutrition support may be medically contraindicated and may be regarded as hopeless treatment if it intensifies the distress of dying [Dresser & Boisaubin, 1985; Lynn & Childress, 1983]. Patients who have the capability to decide typically refuse artificial feeding when they are severely debilitated with little hope of recovery or are near death [Lo, McLeod, & Saika, 1986].

While much attention has been focused on the opinions of physicians and nurses regarding the withholding and withdrawing of food and fluid from terminally ill individuals, a literature search revealed a limited number of articles written about the opinions of registered dietitians regarding this issue. The American Dietetic Association published its position paper on feeding the terminally ill individual in 1992. The paper includes guidelines for determining appropriate uses of nutritional care and proposes an active role for the registered dietitian in creating feeding criteria and in decision making [King & Maillet, 1992]. This study wanted to look into dietitians' opinions, especially since dietitians are invaluable participants with the health care team based on their knowledge about the social, ethical, and legal principles of feeding terminally ill individuals. The study by Wall et al. [1991] examined dietitians'

attitudes toward withholding or withdrawing food and fluid. In their study, dietitians were more willing to discontinue feeding if it caused pain or worsened the condition, if death was imminent or if the patient had requested the feeding be discontinued. Dietitians were more likely to agree to stop feeding because of a patient's request than because of a guardian's request, regardless of the feeding method.

Ethics as a discipline allows an individual to analyze morals and values in a rational manner. One of the most basic precepts of medical ethics and laws is self-determination - the right of an individual to determine his or her own destiny by accepting or rejecting offered medical treatment [Boisaubin, 1984]. The goal of decision making for incompetent patients is the right to self-determination and must be used to determine what decision they would make themselves if they were competent [Annas, 1983]. Nutritional support is well accepted medically, legally, and morally, and should be provided to all patients in the hope of recovery [Boisaubin, 1984]. Nutritional support in the alert and responsive terminally ill patient should be continued if the patient requests it and may indirectly benefit from it [Boisaubin, 1984]. It is imperative for the clinical dietitian to continue to participate in an essential role in the evaluation and decision making concerning the nutritional support of the terminally ill patient [Boisaubin, 1984; King & Maillet, 1992].

### Statement of Purpose

The purpose of this study was to investigate the opinions of Registered Dietitians on the ethical issues involved with the withholding or withdrawing of food and/or fluid in the terminally ill.

### Objective

The objective of this study was:

1. To examine Registered Dietitians' opinions involved in dealing with the ethical issues of withholding and/or withdrawing food and fluid.

### Hypothesis

The hypothesis was:

Registered Dietitians who have experience in using advance directives and living wills will have a more positive attitude toward dealing with the terminally ill than those without such experiences.

## Definition of Terms

1. Terminal illness: the end or final stage of a specific, progressive, normally irreversible, lethal disease when physicians have determined, through objective medical validation, medical treatment of that disease is futile and the disease will cause the patient's death in the foreseeable future [President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research].

2. Death: the irreversible cessation of cardiac and respiratory functions or irreversible cessation of all functions of the entire brain, including the brain stem [President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research].

3. Ethical: pertaining to the processes for determining the most morally desirable course of action in the face of conflicting values choices [Special Committee on Biomedical Ethics, 1985].

4. Living Will: a specific legal format in which an individual can direct that life-sustaining procedures be withheld or withdrawn in the event the individual is in a terminal condition. [Appendix A] A living will goes into effect when: (1) the individual's physician has a copy of it, (2) the physician and another physician have concluded the individual is no longer able to make his or her own health care decisions, and (3) the individual's physician has determined the individual is in a terminal condition or a persistent vegetative state.

5. Durable Power of Attorney for Health Care: [also called "Appointment of Health Care Agent (AHCA)] is a legal document which allows an individual to appoint another individual to make medical decisions in the event the individual becomes temporarily or permanently unable to make those decisions him- or herself. The AHCA becomes effective when the individual becomes temporarily or permanently unable to make his or her own decisions about health care, and the agent agrees to begin making those decisions, but this requires that the physicians have determined the terminal individual is no longer able to make them. The AHCA agent can make almost every treatment decision in accordance with accepted medical practice that the terminal individual could make if he or she were able to do so, and has the duty to act in the best interest of the terminal individual. [Appendix B]

6. Persistent Vegetative State: a patient is in a permanent coma or state of unconsciousness, caused by illness, injury or disease. The patient is totally unaware of him- or herself, his or her surroundings and environment, and to a reasonable degree of medical certainty, there can be no recovery [American Academy of Neurology, 1989].

## Chapter 2

### Review of Literature

Competent, knowledgeable patients, because of their circumstances and values, may refuse various medical treatments, including nutrition support [King & Maillet, 1992]. The fundamental realistic medical goal for caring for the terminally ill individual is compassionate, palliative care [King & Maillet, 1992]. Table 1 lists general guidelines in providing nutritional care for the terminally ill. Specifically, what is shown is how each case should be handled individually with the patient's wishes used as the primary guidelines for determining the form of nutrition intervention. Because each terminally ill individual is unique, care should be constantly reevaluated. Reducing pain, psychological distress, and symptoms without actually attempting to cure is the focus of palliative care; therefore, continuous evaluation of the wide range of symptoms is imperative [Annas, 1986; King & Maillet, 1992]. Maintaining or restoring health through nutrition is the main objective of nutritional support [La Puma, Orentlicher, & Moss, 1991]; therefore, all patients should be provided nutrition support if requested and if they might benefit from it [Boisaubin, 1984; King & Maillet, 1992]. Table 2 lists considerations for providing aggressive nutrition support; and specifically, whether nutrition support will improve the quality of life of the terminally ill patient.



## TABLE 1

### GENERAL CONSIDERATIONS REGARDING NUTRITION CARE FOR THE TERMINALLY ILL ADULT

- A. Each case is unique and must be handled individually.
- B. The patient's expressed desire for extent of medical care is the primary guide for determining the level of nutrition intervention.
- C. The expected benefits, in contrast to the potential burdens, of non-oral feedings must be evaluated by the medical care team and discussed with the patient. The focus of care should emphasize patient comfort.
- D. The decision to withhold hydration or nutrition support should be weighed carefully because such a decision may be difficult or impossible to reverse within a period of days or weeks.
- E. The decision to withhold "heroic" medical treatment does not preclude baseline nutrition support.
- F. The physician's written diet order in the medical chart documents the decision to feed or to withhold nutrition support. The dietitian should participate in this decision.
- G. The institution's ethics committee, if available, should assist in establishing and implementing defined, written guidelines for feeding the terminally ill. The dietitian should be a required member of or consultant to such a committee.

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King, D.G. and Maillet, J. (1992). Position of the American Dietetic Association: Issues in feeding the terminally ill adult. JADA 92(8):996-1005.

## TABLE 2

### CONSIDERATIONS FOR EXAMINING THE EFFICACY OF PROVIDING AGGRESSIVE NUTRITION SUPPORT

- A. Will nutrition support, either oral or mechanical, improve the patient's quality of life during the final stages of morbidity by increasing physical strength or resistance to infections?
- B. Will nutrition support, either oral or mechanical, provide the following to the patient: emotional comfort, decreased anxiety about disease cachexia, improved self-esteem with cosmetic benefits, improved interpersonal relationships, comfort or relief from the fear of abandonment?
- C. Oral feedings are the preferred choice. Tube feeding is generally the next logical step. Parenteral nutrition should be considered only when other routes are impossible or inadequate to meet the comfort needs of the patient.
- D. Oral Intake
  1. Oral feeding should be advocated whenever possible. Food and control of food intake may give comfort and pleasure. The most important priority is to provide food according to the patient's individual wishes.
  2. Efforts should be made to enhance the patient's physical and emotional enjoyment of food by encouraging staff and family assistance in feeding the debilitated patient.
  3. Nutrition supplements, including commercial products and other alternatives, should be used to encourage intake and ameliorate symptoms associated with hunger, thirst or malnutrition.
  4. The therapeutic rationale of previous diet prescriptions for an individual patient should be re-evaluated. Many dietary restrictions can be liberalized. Coordination of medication or medication schedules with the diet should be discussed with the physician, with the objective of maximizing food choice and intake by the patient.

5. The patient's right to self-determination must be considered in determining whether to allow the patient to consume foods that are not generally permitted within the diet prescription.

E. Tube feeding or parenteral feeding

1. Palliative care is the usual realistic goal; however, a palliative care plan does not automatically preclude aggressive nutrition support.
2. Facilities should provide and distribute written protocols for the provision of and termination of tube feedings and parenteral feedings. The protocols should be reviewed periodically, and revised if necessary, by the health care team. Legal and ethical counsel should be routinely sought during the development and interpretation of the guidelines.
3. The patient's informed preference for the level of nutrition intervention is paramount. The patient or guardian should be advised on how to accomplish feeding if the patient wants maximal nutrition care.
4. Feeding may not be desirable if death is expected within hours or a few days and the effects of partial dehydration or the withdrawal of nutrition support will not adversely alter patient comfort.
5. Potential benefits vs. burdens of tube feeding or parenteral feeding should be weighed on the basis of specific facts concerning the patient's medical and mental status, as well as on facility options and limitations.

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King, D. and Maillet, J. (1992). Position of The American Dietetic Association: Issues in feeding the terminally ill adult. JADA 92(8):996-1005.

Support would be indicated if the patient desires it or was able to benefit from it by enjoying the taste, feeling stronger or sensing more optimism [La Puma, Orentlicher, & Moss, 1991]. However, there would appear to be no advantage to continuing nutritional support in the unresponsive terminal patient because no benefit can occur [Boisaubin, 1984]. In a study by McCann, Hall, and Groth-Juncker [1994], patients with advanced cancer and malnutrition experienced no benefit from aggressive nutritional support on morbidity or mortality. Table 3 lists considerations for not providing aggressive nutrition support including questions to determine the potential burdens of nutrition support.

If the placement of the nasogastric tube is frightening and painful to the incompetent patient, and if maintaining the tube requires taping it to the face or arm and restraining the patient, then this activity may not always be in the best interest of the patient, whether or not it is characterized as medical treatment [Annas, 1986]. If the patient is in no observable pain or discomfort with the nasogastric tube and if removing the tube will create a slow and painful death, then removal is not warranted [Annas, 1986]. On the other hand, if the patient is in pain and discomfort due to the nasogastric tube itself, and there is no hope of patient recovery, removal of the tube may be appropriate, since the pain of starvation may be less than that of postponing the process of dying [Annas, 1986].

TABLE 3

CONSIDERATIONS FOR EXAMINING THE EFFICACY OF  
WITHHOLDING AGGRESSIVE NUTRITION SUPPORT

- A. Questions that can help to determine the potential burdens include:
1. What is the level of risk for potential medical and metabolic complications from each available nutrition alternative?
  2. Will the administration of tube feeding or Total Parenteral Nutrition at home or in a health care facility be contraindicated because of staffing, monitoring ability or financial constraints?
  3. Will the nutritional benefits of the insertion of an enteral or parenteral feeding tube during hospitalization create feelings of abandonment if tube feeding is unavailable upon discharge?
- B. Withholding or discontinuing enteral or parenteral nutrition support may be considered when some or all of the following are present:
1. Death is imminent, within hours or a few days.
  2. Enteral or parenteral feeding will probably worsen the condition, symptoms or pain, such as during shock, when pulmonary edema or diarrhea, vomiting or aspiration would cause further complications.
  3. A competent patient has expressed an informed preference not to receive aggressive nutrition support which would be ineffective in improving the quality of life and/or which may be perceived by the patient as undignified, degrading, and physically or emotionally unacceptable.
  4. If available and legally recognized, written advanced directives such as the "living will" or "durable power of attorney for medical care" may indicate the preference of an incompetent patient. Otherwise, the next of kin or patient appointed guardian of an incompetent patient should be consulted about the patient's probable preference for the level of nutrition intervention, as well as state law.
- C. Written ethical guidelines for assessing and implementing these considerations should be established through the facility's ethics committee, if available, and in accordance with legal guidance.

- D. Legal precedents and regulations or statutes establishing feeding parameters within local and state jurisdiction should be considered when deciding to require or forego nutrition support. The facility's written protocol and legal counsel should also be consulted.

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King, D. and Maillet, J. (1992). Position of The American Dietetic Association: Issues in feeding the terminally ill adult. JADA 92(8):996-1005.

The appropriate description of "do not resuscitate" or "no cardiopulmonary resuscitation" condition does not automatically circumvent other aggressive medical interventions, such as parenteral nutrition or enteral nutrition, if that is what the patient desires and it is available [Emanuel, 1988]. These interventions may be considered as an inhumane means of prolonging the emotional and physical anguish at the cessation of life [King & Maillet, 1992].

Indigenous to any aspect of informed consent is the idea of an individual's constitutional right to privacy, which includes the privilege to be left alone and not invaded or treated against his or her will, including the surgical and nonsurgical insertion of all feeding tubes [King & Maillet, 1992; La Puma, Orentlicher, & Moss, 1991]. However, the patient's lawful and moral right of self-determination, as assured by the expressed consent doctrine, is not absolute [King & Maillet, 1992].

The State may execute its authority to restrict the right of personal independence on the basis of several concepts: [a] the preservation of life, [b] the prevention of suicide, [c] the protection of innocent third parties (especially the financial and emotional interests of minor children), and [d] the protection of the ethical integrity and professional discretion of the medical profession [La Puma, Orentlicher, & Moss, 1991].

### Historical Background

The most prominent historical case involving the withdrawal of

life-sustaining medical care from a permanently incompetent adult was the Quinlan case [Annas, 1976; Emanuel, 1988]. Karen Quinlan was a 21-year-old who stopped breathing for two fifteen-minute periods. She was unresponsive to deep pain, with her pupils unreactive, and she was placed on a respirator after resuscitation. She became dependent on the respirator within three days. She was receiving nutrition via nasogastric tube, was respirator dependent, and in a chronic persistent vegetative state one year later. After much discussion with his priest, Karen's father requested the respirator be discontinued; however, her attending physicians refused, viewing this as a violation of medical ethics [Annas, 1976]. Also, the local prosecutor and state attorney general threatened criminal prosecution.

The judges on the Quinlan case concluded an individual's constitutional right to privacy included a right to refuse medical care and recognized this right for incompetent patients, and this right applied to Karen's "artificial life-support apparatus" [Annas, 1976; Emanuel, 1988]. Second, the judges argued the guardian of a patient who would never "return to a cognitive and sapient existence" could disconnect a respirator [Annas, 1976; Emanuel, 1988]. Third, a "hospital ethics committee" should verify the patient's prognosis, to dispel responsibility, and to isolate the decision makers from prosecution [Annas, 1976; Emanuel, 1988]. Finally, the judges argued the typical process is to prefer the next of kin as the patient's guardian; therefore, granting Karen's father "full



power to make decisions" [Annas, 1976; Emanuel, 1988]. The court stressed decisions for terminating care should not need prior judicial review, and never specified a standard for terminating care, but viewed Karen's respirator as "extraordinary" care [Annas, 1976; Emanuel, 1988].

According to Annas [1985], the court wanted the respirator to be disconnected from Karen, and created a method designed to help physicians feel better about disconnecting the machine. However, the court ignored Karen's right to refuse treatment and focused on the physicians and their fear of liability, issuing an ill-defined and potentially harmful opinion permitting Karen's family, guardian, and physician to do almost anything they wanted to her with legal immunity [Annas, 1976].

Since the 1976 case of Karen Ann Quinlan, courts and society have debated on how to make decisions for individuals who are incompetent. The general inclination of all parties has been to respect the previously expressed wishes of such patients as an extension of respecting their autonomy [Wachter & Lo, 1993]. The current debate evolved around the following question: How specifically do patients need to express their wishes for them to be respected? The high level of emotional content and conflict surrounding this issue was demonstrated by the intense debate over the case of Nancy Cruzan and the subsequent U.S. Supreme Court decision. Nancy Cruzan was a 33-year-old woman who entered a persistent vegetative state, with permanent, irreversible

brain damage following an automobile accident in 1983. She had no cognitive or reflexive ability to swallow food or water and her highest cognitive function was exhibited by grimacing in response to painful stimuli [Wachter & Lo, 1993].

In 1986, after realizing her condition would not improve, her family asked that the tube feedings, which began in 1983, be discontinued [Cruzan v Harmon, Missouri Supreme Court, 1988]. The hospital insisted on a court ruling. Medical experts testified that although there is no hope of recovery, she is not terminally ill and could live years [Cruzan v Harmon, Missouri Supreme Court, 1988]. In July, 1988, a Missouri trial court ruled that the feedings could be withheld [Cruzan v Harmon, Missouri Supreme Court, 1988]. The ruling was based partly on the statement Nancy Cruzan made prior to her accident that she "did not want to live" as a "vegetable" [Cruzan v Harmon, Missouri Supreme Court, 1988]. Her family interpreted this statement as indicating that, if she were competent, Nancy Cruzan "would not want to continue living in her condition" [Cruzan v Harmon, Missouri Supreme Court, 1988].

In November 1988, the highest Court in Missouri reversed the trial court's decision, rejecting legal precedents adopted by other states which recognize that a permanently comatose patient has a constitutional "right to privacy" that can even be exercised by the patient's family members in withholding or withdrawing all life-sustaining medical treatment, including nutrition and fluid [Wachter & Lo, 1993]. In a reference to previous court

decisions the Missouri court stated:

"It is our legal duty in a case of first impression in this state not only to consider precedents from other states, but also to determine their strength. We have found them wanting and refuse to eat 'on the insane root which takes reason prisoner.'"

[Fiesta, 1993].

On June 25, 1990, by a 5 to 4 vote, the Supreme Court agreed with the decision by the Missouri Supreme Court [Fiesta, 1993]. The Supreme Court ruled that although competent adults have a "constitutionally protected liberty interest in refusing unwanted medical therapy," [Wachter & Lo, 1993], incompetent patients lack this right because they are unable to exercise it directly; therefore, states may establish "procedural safeguards," regulating decisions for incompetent patients that are more stringent than what would be required for a competent patient [Wachter & Lo, 1993]. The highest court's decision is a narrow decision which defers to the individual state's right to require that clear and convincing evidence is necessary to withdraw life-sustaining treatment from an incompetent patient [Wachter & Lo, 1993]. In the Cruzan case, the family members provided the only available information about the patient's wishes; therefore, the Court agreed that the state's requirement of clear and convincing evidence had not been met [Wachter & Lo, 1993].

The Cruzan decision has been harshly criticized by some lawyers,

ethicists, and physicians [Lo & Steinbrook, 1991]. The critics say the decision undermines the authority of families to make decisions for their loved ones and encourages the practice of defensive medicine [Lo & Steinbrook, 1991; Wachter & Lo, 1993]. Also, the insistence of "clear and convincing evidence" places the burden on the poor and disenfranchised, who have fewer chances to place such evidence in writing [Lo & Steinbrook, 1991; Wachter & Lo, 1993]. Finally, and more importantly, the Supreme Court's decision creates a presumption that individuals would want their lives sustained even if terminally ill or permanently unconscious; advance directives are required to overcome this presumption [Wachter & Lo, 1993]. Six months after the United States Supreme Court decision, three new witnesses testified of Nancy's wishes to discontinue the life-sustaining medical treatment. The court case was subsequently dismissed and the court granted permission for the feeding tube to be removed. The court's decision stresses the need for patients to have written directives. The use of health care proxies would have made the court case unnecessary [Maillet, 1995].

Claire C. Conroy, an unmarried, eighty-four year old female resident of Parkland Nursing Home in Bloomfield, New Jersey, was suffering from severe organic brain syndrome, chronic decubitus ulcers, urinary tract infection, heart disease, hypertension, and diabetes [Annas, 1983 & 1985]. She had primitive brain function, was unaware of her surroundings, had no cognitive ability, with

no expectation her condition would improve [Annas, 1983 & 1985]. Her nephew and only surviving relative, Thomas Whittemore, was appointed her legal guardian in August, 1979, after she was determined incompetent. Ms. Conroy was then placed in a nursing home. In 1982, Ms. Conroy was admitted to the hospital with a gangrenous leg for treatment. Mr. Whittemore refused consent for amputation which was recommended to prevent death, stating Ms. Conroy would not have consented were she competent. Ms. Conroy survived, although the surgery was never performed [Annas, 1983 & 1985].

A nasogastric tube was inserted to facilitate feeding because of Ms. Conroy's inability to consume adequate nutrition by mouth; however, Mr. Whittemore requested the tube be removed, but her physician refused. Mr. Whittemore filed suit for the removal of the feeding tube, and the trial court ruled for the removal; however, the Appellate Division reversed the decision, ruling the termination of the feeding would be homicide [Annas, 1985]. Ms. Conroy died in February, 1983, with the feeding tube still in place.

The case went to the New Jersey Supreme Court which ruled the termination of any medical treatment, including artificial feeding, for incompetent patients lawful under certain circumstances: [a] "subjective test": when there is clear and reliable evidence (living will) indicating what the patient would have chosen if he or she were competent, the surrogate decision maker should choose the treatment outcome most consistent with that evidence; [b] "limited

objective" test: when there is only a general indication a patient would refuse life-sustaining intervention if competent, treatment may be withdrawn only if "the burdens of the patient's continued life with the treatment outweigh the benefits of that life for him" (objective benefit-burden analysis); and [c] "pure objective" test: if no evidence at all is available concerning the patient's preferences while competent, it is permissible to terminate treatment if the net burdens of continued life "clearly and markedly" outweigh the benefits [Dresser, 1985].

The court based its decision on an individual's common law right to agree or reject any medical treatment "under the doctrine of informed consent, which is designed to protect the patient's ability to control his bodily integrity," and encompasses "the right to decline to have any medical treatment initiated or continued" [Matter of Conroy, 1983]. The court concluded:

"We have no doubt that Ms. Conroy, if competent to make the decision and if resolute in her determination, could have chosen to have her nasogastric tube withdrawn" [Matter of Conroy, 1983].

In 1982, two Los Angeles physicians removed a respirator and intravenous feeding from a patient whose brain had totally ceased to function, and were later charged with murder [Steinbock, 1983]. On August 24, 1981, Clarence Herbert, a fifty-five year old security guard, was admitted to Kaiser-Permanente Hospital to undergo surgery by Dr. Nejdli to remove a

colostomy bag, which had been inserted a few months before to relieve a bowel obstruction problem [Steinbock, 1983]. Mr. Herbert went into cardiopulmonary arrest during his first hour in the recovery room, became comatose, and was placed on a respirator. Dr. Freedman, the hospital neurologist, diagnosed Mr. Herbert with severe brain damage, with no motor function and impaired brain stem function due to lack of oxygen. The next morning, the attending internist, Dr. Barber, spoke with Mrs. Herbert, who agreed to take her husband off the respirator. The wishes of the family were consistent with Mr. Herbert's who stated he did not want to be kept alive by machines [Steinbock, 1983].

Taking a patient whose brain has totally ceased to function off a respirator is clearly permitted by California's brain death law, Section 7180 of the Health and Safety Code [Steinbock, 1983]. However, when the respirator was disconnected, Mr. Herbert did not die but continued to breathe on his own. Mrs. Herbert and other family members signed a consent form the next day, stating the family wanted "all machines turned off " [Steinbock, 1983]. On August 31, at 8:00 A.M., Dr. Barber ordered all intravenous feeding disconnected; Dr. NejdI ordered the feeding tube discontinued shortly afterwards. Mr. Herbert died from pneumonia and dehydration on September 6. Sandra Bardenilla, a nursing supervisor, then went to the authorities [Steinbock, 1983].

The cessation of artificial feeding initiated the decision to prosecute which was seen as significantly different from the mere removal of a respirator from a

permanently comatose patient [Steinbock, 1983]. The prosecution alleged that even the disconnection from the respirator, presumably legal in other contexts, should be considered murder because it was part of a conspiracy to kill Mr. Herbert to hide malpractice [Steinbock, 1983]. Finally, the suggestion was made that Mr. Herbert was not, or was not known to be, permanently comatose when the intravenous tubes were disconnected and that he might have recovered had the tubes not been removed [Steinbock, 1983].

On March 9, 1983, Municipal Court Judge Brian Crahan dismissed the charges against the doctors, stating that there was no evidence of malicious intent, and hence no evidence to sustain murder charges; however, he warned this dismissal did not rule out criminal charges in other cases [Steinbock, 1983].

Decisions involving artificial feeding have provoked more controversy than those pertaining to any other life-sustaining intervention [Lo & Steinbrook, 1991]. Because food and water are typically considered basic elements of humane treatment, depicting love and concern for the helpless, it is frequently thought they have to be provided [Lynn & Childress, 1983].

In a landmark decision by the Supreme Judicial Court of Massachusetts in 1986, the Court ruled a feeding tube could be discontinued in a 49-year-old man in a persistent vegetative state, according to his wishes not to live as a "vegetable" [Brophy v New England Sinai Hospital, Inc., 1985]. Paul E. Brophy, Sr., was a former emergency medical technician and firefighter who underwent



unsuccessful surgery in April 1983 for a ruptured basilar-artery aneurysm, and never regained consciousness [Steinbrook & Lo, 1988]. Brophy was transferred in a persistent vegetative state to a convalescent hospital in June of the same year. In August, Paul Brophy contracted pneumonia and his physicians and his wife and legal guardian, Patricia Brophy, agreed not to resuscitate him in the event Brophy went into cardiac arrest [Steinbrook & Lo, 1988]. In December 1983, Mrs. Brophy agreed to the surgical insertion of a gastrostomy tube [Steinbrook & Lo, 1988].

Although Brophy never specifically discussed artificial feeding, he had repeatedly told family members to "pull the plug" if he should ever end up in a coma [Steinbrook & Lo, 1988]. Just prior to his own neurosurgery, Brophy told his daughters, "If I can't sit up to kiss one of my beautiful daughters, I may as well be six feet under" [Steinbrook & Lo, 1988]. Mrs. Brophy concluded her husband's active life was over when his condition remained unchanged through 1984, and began to question the provision of the feeding tube [Steinbrook & Lo, 1988]. Although the couple's five children and family members supported Mrs. Brophy's decision to stop the feeding, her husband's physicians and the hospital administration were opposed [Lo & Steinbrook, 1991; Steinbrook & Lo, 1988].

In February 1985, Mrs. Brophy petitioned a probate court to allow her husband's feeding tube to be stopped. In December, the probate judge ruled the feeding must continue, although the judge found that Brophy would rather be

dead than have his life prolonged in a persistent vegetative status and concluded if Brophy were competent, he would refuse artificial feeding [Brophy v New England Sinai Hospital, Inc., 1985]. Mrs. Brophy appealed, and in September 1986, the Massachusetts Supreme Judicial Court ruled in a 4-to-3 decision that Brophy's artificial feeding could be discontinued [Brophy v New England Sinai Hospital, Inc., 1985; Lo & Steinbrook, 1991; Steinbrook & Lo, 1985]. On October 23, 1986, eight days after the artificial feeding was stopped, Brophy died of pneumonia at the age of 49 [Brophy v New England Sinai Hospital, Inc., 1985; Lo & Steinbrook, 1991; Steinbrook & Lo, 1985].

The Court based the ruling on common law and the constitutional right of patients to refuse medical treatment, regardless of whether other individuals consider the refusal as unwise [Brophy v New England Sinai Hospital, Inc., 1986]. The majority decision stated "to be maintained by such artificial means over an extended period is not only intrusive but extraordinary" [Brophy v New England Sinai Hospital, Inc., 1986]. The decision also rejected a distinction between withholding and withdrawing intervention already initiated, including artificial feeding, stating that if withdrawing treatment is seen as more complicated than withholding it, this difference could discourage efforts at different types of care and lead to premature decisions to allow patients to die [Brophy v New England Sinai Hospital, Inc., 1985; Lo & Steinbrook, 1991; Steinbrook & Lo, 1988].

The court said Brophy's right to refuse medical intervention, including artificial feeding, outweighed three state interests favoring continued treatment: [a] the ethical integrity of the medical profession, [b] the prevention of suicide, and [c] the preservation of life [Brophy v New England Sinai Hospital, Inc., 1985; Lo & Steinbrook, 1991; Steinbrook & Lo, 1988]. The main decision ascertained that the ethical integrity of the medical profession would not be violated as long as health care providers were not discontinuing feedings against patients' will. The courts ruled Brophy's physicians and the hospital could not be forced to withhold artificial feedings from him if these actions went against their "view of their ethical duty toward their patient" [Brophy v New England Sinai Hospital, Inc., 1986]. Instead, the court ordered the hospital to help Mrs. Brophy in transferring her husband to another site where his desires could be carried out [Lo & Steinbrook, 1991; Brophy v New England Sinai Hospital, Inc., 1986].

With regard to the prevention of suicide, the court ruled that the stopping of artificial feeding would not represent direct killing or suicide, nor would it subject Brophy to a painful death by starvation, but merely allow the underlying disease to take its natural course [Lo & Steinbrook, 1991; Brophy v New England Sinai Hospital, Inc., 1986]. As to the preservation of life, the court reasoned that the state had no right to preserve life when the patient believed the means of doing so degraded his or her humanity [Lo & Steinbrook, 1991; Brophy v New England Sinai Hospital, Inc., 1986]. Only Brophy could decide

about the quality of his life - not the physicians or third parties, including the court [Lo & Steinbrook, 1991]. Although Brophy was not terminally ill, he had a right to refuse life-sustaining intervention, including artificial feeding [Lo & Steinbrook, 1991].

The courts have established that competent adults have the right to reject treatment, including artificial feeding [Annas, G., 1986]. This was the case in December 1984 when a California Court of Appeals made an important ruling upholding the right of competent patients to refuse life-sustaining treatment [Lo, 1986]. In the Bartling case, the physicians believed their duty to respect the patient's wishes clashed with their duty not to harm the patient [Lo, 1986].

William Bartling, a 70-year-old, had a long history of smoking, chronic obstructive lung disease, depression, and coronary artery disease. He was admitted to a hospital in April 1984 due to back pain and depression. His chest x-ray upon admission showed a new pulmonary nodule which was later identified as adenocarcinoma. He later suffered a pneumothorax and required a chest tube and mechanical ventilation [Lo, 1986].

After two months, he was unable to be weaned from the respirator and asked for the respirator to be disconnected and signed a durable power of attorney for health care, a living will, and a declaration of his wishes [Lo, 1986]. His family signed documents releasing both the hospital and physicians from liability; however, the physicians and hospital refused the request and attempted

to transfer the patient to another hospital that would honor his wishes but failed [Lo, 1986]. In June 1984, the Superior Court heard the case and ruled against the patient. Mr. Bartling died while still on the respirator before the case was heard by the Court of Appeals.

The hospital and physicians argued against disconnecting the respirator because Mr. Bartling changed his wishes due to his depressed state. A nurse testified Mr. Bartling told her he wanted to live on the same day he signed a declaration to disconnect the respirator [Lo, 1986]. She later heard Mr. Bartling tell the psychiatrist he wanted to die. The court rejected this argument based on the fact that the patient had signed several documents expressing his wish to disconnect the ventilator declaring,

"The fact that Mr. Bartling periodically wavered from this posture because of severe depression or for any other reason does not justify the conclusion...that his capacity to make such a decision was impaired to the point of legal incompetency" [Bartling v Superior Court, 1986].

The second point the hospital and physicians argued for continuing the respirator was based on their ethical duty to preserve life stating withholding life-sustaining treatment was incompatible with their Christian and pro-life beliefs [Bartling v Superior Court, 1986]. The court rejected this argument as well declaring,

"If the right of the patient to self-determination as to his own medical treatment is to have any meaning at all, it must be paramount to the interests of the patient's hospital and doctors" [Bartling v Superior Court, 1986].

This decision maintained competent patients have the right to refuse life-sustaining treatment, even if they are not terminally ill or comatose regardless of whether the doctors disagree due to conscience or ethics [Lo, 1986]. The court reassured hospitals and physicians they, "...could not have been criminally or civilly liable for carrying out his (the patient's) instructions" [Bartling v Superior Court, 1986]. The court also ruled the hospital and physicians did not need prior judicial approval before withdrawing treatment [Bartling v Superior Court, 1986].

In our entire constitutional tradition, respect for life has been one of the fundamental values shaping the fabric of our society [Kane, 1985]. In today's society, the desire for a certain quality of life supersedes the mere value of life [Kane, 1985]. This was the case with Elizabeth Bouvia, the California woman severely afflicted with cerebral palsy. Ms. Bouvia requested that the court mandate the cooperation of Riverside County Hospital in her plan to starve herself to death. Ms. Bouvia entered Riverside County Hospital as a psychiatric admission, seeking treatment for suicidal depression. Instead of accepting offers to enter private homes to end her life, Ms. Bouvia wanted to establish a

legal precedent for a state-assisted suicide [Kane, 1985]. Judge John Hews of the California Superior Court however, ruled against Ms. Bouvia stating society values life and "society's interest in preserving life and the medical profession's obligation to do so outweighed her right to self-determination" [Kane, 1985]. If Ms. Bouvia had not requested interference or had refused treatment, her right of autonomy and self-determination would have been valid and her wishes would have been respected [Kane, 1985]. However, because Ms. Bouvia wanted the assistance from doctors, nurses, and hospital staff, others would have been forced into violating not just their individual consciences but their professional codes of ethics [Kane, 1985].

Had Judge Hews accepted the argument that the desire for quality of life supersedes the value of life, he would have accepted Ms. Bouvia's argument that there was no longer any point for her to continue to live in what she referred to as her "useless body" [Kane, 1985]. According to Kane [1985], Judge Hews made the wiser choice in refusing Ms. Bouvia's request, and stated,

"It was not their recognition of a certain quality of life that led the founders of the republic to proclaim the inalienable right to life but the value of life itself. If every life is valued, then every life must be valued, even one's own" [Kane, 1985].

Assisting or participating in taking life would violate for what a civic community

stands [Kane, 1985].

### Advance Directive/Living Wills

The privilege of individual self-determination and power over medical decisions is protected by the due process clause of the 14th Amendment of the United States Constitution [Annas, 1986]. For incompetent patients, family members and caretakers should try to establish the patient's desires; however, establishing what is "clear and convincing evidence" of incompetent patients is difficult [Lo & Steinbrook, 1991]. The use of advance directives and patient-appointed surrogates will help "determine the clear and convincing standard in an operational manner" [Lo & Steinbrook, 1991]. Legal rationale and precedent exist for respecting a patient's explicit wishes regarding nutrition and hydration [McCann, Hall, & Groth-Juncker, 1994]. Patients' wishes about life-sustaining treatments are not entirely stable over time, though choices to forgo life-sustaining treatment seem to be much more stable than choices to receive such treatment [Danis, 1994]. Patients are often unable to participate in the decision to use life-sustaining treatments when necessary; therefore, advance directives such as the living will have been developed to preserve their autonomy [Danis, Southerland, Garrett, Smith, Hielema, Pickard, Egner, Patrick, 1991]. For patients who do not have advanced directives, it is now legal in an increasing number of states, without going to court, for physicians to rely on consent to withhold or withdraw medical treatment obtained from designated



relatives; in most of these states, however, the patient must be terminally ill [Areen, 1987].

Surveys of the general public [Emanuel, Barry, & Stoeckle, 1991; Gamble, McDonald, & Lichstein, 1991; Steiber, 1987], nursing home residents [Danis, Southerland, Garrett, Smith, Hielema, Pickard, Egner, Patrick, 1991], and outpatients [Emanuel, Barry, & Stoeckle, 1991] suggests precisely the opposite: 80% to 90% of individuals would not want life-sustaining intervention if they were permanently terminally ill or unconscious; therefore, the critics argue that society's "default mode" should be that individuals with certain specific irreversible states of neurological impairment will not receive life-sustaining intervention unless they have provided advance directives to the contrary [Thomasma, 1991].

Despite the criticisms stated above, there has been a wide range of support within the legal and bioethical communities [Wachter & Lo, 1993]. First, the Supreme Court indicated that the refusal of therapy for informed and competent patients is protected by the Constitution, even if such patients are not terminally ill [Wachter & Lo, 1993]. It has been recognized by the courts that the termination of life support is neither suicide, murder nor assisted suicide [Meisel, 1991]. Judicial opinions furnish three reasons why this is so: (a) a patient's death due to the termination of life support is not criminal because the patient's medical condition - rather than the termination of life support - is the cause of

death. The removal of life support merely allows nature to take its course; (b) when life support is terminated at the request of a competent patient, the intent is to bring relief from suffering, whereas in cases of genuine suicide the individual's intent is to bring about his or her own death; and (c) such behavior involves the practice of a patient's legal right to refuse medical treatment, and thus "it follows that by exercising these rights, the individual cannot become criminally liable" [Meisel, 1991].

There are difficulties with the first and second reasons. The first assumes a theory of causation that is not widely accepted; namely, that there is a single cause of death - the patient's medical condition - and that the behavior of the physician is not causal [Meisel, 1991]. The second reason does not differentiate between death, the termination of life support, and suicide since individuals who are not terminally ill and who commit suicide are also suffering and they also may wish death as a release from suffering [Meisel, 1991]. Treatments such as artificial nutrition and hydration are to be considered "medical treatments" that may be refused as readily as cardiopulmonary resuscitation [Wachter & Lo, 1993]. The Supreme Court strongly supported the use of formal advance directives, to express what treatments a patient would have wanted and who could best represent his or her wishes [Wachter & Lo, 1993]. Eight of the nine U.S. Supreme Court justices in the Cruzan case stated the 14th Amendment guarantees a constitutional right to avoid unwanted medical treatment. The

constitutional right to refuse unwanted medical procedures implies discontinuance of life-sustaining treatment in cases where a person has clearly and legally documented such wishes. The justices' interpretation supported the use of living wills and other documents that clearly express an individual's requests concerning life-prolonging procedures.

Although both physicians [Thomasma, 1991] and patients [Emanuel, Barry, & Stoeckle, 1991] also support the use of advance directives, less than 20% of the American population have completed them [La Puma, Orentlicher, & Moss, 1991]. Reasons for their infrequent use include [a] discomfort with their use on the part of patients or physicians, [b] ignorance about advance directives, and [c] a belief directives are only useful for the ill and elderly [La Puma, Orentlicher, & Moss, 1991]. The infrequent use of advance directives motivated the United States Congress to enact the Patient Self-Determination Act (PSDA) of 1990, which went into effect on December 1, 1991 [Omnibus Budget Reconciliation Act, 1990]. The Act requires all health care institutions receiving federal funding advise patients at the time of admission into the hospital of their right to refuse medical care and to execute advance directives [King & Maillet, 1991].

Advance directives and living wills continue to be the preferred solution for treatment decisions for incompetent individuals [Robertson, 1991]. They are recommended by most advisory bodies and medical ethicists, and have

achieved judicial or legislative recognition in more than forty states [Robertson, 1991]. Through the Patient Self-Determination Act, federal law encourages the use of advance directives and living wills by requiring hospitals to inform patients of their right to make such directives [Robertson, 1991].

The appeal for advance directives and living wills lies in the fact that they do give competent individuals a sense of control over decisions for the future if they become incompetent and thus empowers individuals by expanding the range of personal autonomy to circumstances in which autonomy cannot be directly practiced [Robertson, 1991]. If specific enough, living wills also provide workable guidelines for nontreatment decisions that appear to respect autonomy without compounding respect for incompetent patients. Therefore, they play an important part in achieving the now widely accepted recognition that treatment can be withheld from both competent and incompetent patients [Robertson, 1991].

However, despite these advantages, living wills and advance directives have not been befriended by those they are intended to protect. Surveys indicate very few individuals have them [Emanuel & Emanuel, 1989], and even when they do, doctors are sometimes unwilling to follow them [Robertson, 1991A]. According to Danis [1994], advance directives were not followed when the preference in the directive was too restrictive to allow care that the family or care provider believed to be appropriate at the moment of

illness, or when the family or care provider did not believe the preferred care would be of benefit to the patient.

#### Hydration for the terminally ill

A statement regarding the difference between ordinary and extraordinary care for the dying patient has been in existence for more than thirty years [Pius XII, 1958]. Although the difference has been abandoned by most medical ethicists, clinicians use this difference considering intravenous fluids ordinary and standard care [Micetich, Steinecker, & Thomasma, 1983]. This may be due in part to the notion that individuals have a moral urge to feed the hungry and to give something to drink to those who are thirsty [Printz, 1992]. There is the assumption that terminally ill patients must be hungry because most do not eat or drink anything; therefore, they should receive artificial hydration and/or nutrition [Printz, 1992]. Although research is limited in this area, there are some studies which say the exact opposite and that they are more comfortable without any nutritional intervention [Oliver, 1984; Printz, 1988; Zerwekh, 1983]. According to Printz [1988], dying patients were more comfortable, with less distress, and aware of less pain, with less hydration than physiologically hydrated patients. Therefore, some would argue these individuals are being subjected to a treatment which may be uncomfortable to them [Printz, 1992]. There has been widespread support from major religious groups that nutrition and hydration may at times be considered unnecessary forms of therapy

[Gershan, 1985; McHughes, 1990]. Unwanted nutritional support and hydration through intravenous or enteral routes may not only be ineffective in reducing morbidity in patients with advanced cancer, but may be associated with an increase in medical complications and reduction in quality of life [Clamon, Field, & Evans, 1985; Koretz, 1984; Nixon, Moffitt, & Lawson, 1981].

Food and drink have been symbolic of compassion; therefore, artificial nutrition and hydration is also equated with showing care and compassion to the terminally ill patient [Printz, 1992]. According to Seigler and Weisbard [1985], providing fluids to the terminally ill patient provides an important social, psychological, and clinical barrier which should be maintained. Some argue that this treatment cannot be withdrawn once initiated because it would contribute to the devaluation of the terminally ill patient's life and could lead to the death of certain groups of individuals [Derr, 1986]. This is typically known as "slippery slope theory" [Derr, 1986].

Human beings demand respect, regardless of their current functional status [Micetich, Steinecker, & Thomasma, 1983]. Therefore, it can be argued that this philosophy of respecting life requires the provision of minimum fluids necessary to maintain life [Micetich, Steinecker, & Thomasma, 1983]. Similarly, though there is no obligation for prolonging life, there is a continued obligation to provide care [Micetich, Steinecker, & Thomasma, 1983]. Providing food and fluids only as needed to relieve the patients discomfort can be an effective

means of fulfilling a patient's wishes while alleviating discomfort. Caregiver time can be spent providing comfort care for patients rather than implementing artificial food and fluid. Therefore, Ramsey [1980] argues:

"When a man is irreversibly in the process of dying, to feed him and to give him drink to ease him and to keep him comfortable - these are no longer given as a means of preserving life. The use of a glucose drip should often be understood in this way. This keeps a patient who cannot swallow from feeling dehydrated, and is often the only remaining 'means' by which we can express our present faithfulness to him during his dying."

Caring for someone who is dying can create emotional responses, especially frustration. This is particularly evident in one who is caring for the patient receiving extensive treatment who will never reach a cognitive status [Printz, 1988]. Withdrawing life-sustaining procedures which have already been initiated creates even deeper emotional responses [Printz, 1988] and is psychologically difficult [Micetich, Steinecker, & Thomasma, 1983]. This may be due in part to the fact that it is easier to act in the face of death rather than to refrain from doing nothing [Micetich, Steinecker, & Thomasma, 1983].

Physicians and nurses are hesitant to remove medical hydration in a

patient who is involuntarily receiving hydration because it may be viewed as unethical and illegal [Printz, 1988]. According to Annas [1986],

"If a gastrostomy tube can never be removed or clamped once it is put in place, then the only strategy patients and their families can employ is always to refuse all gastrostomy tube placements if they believe they will want their use discontinued when and if it becomes clear they cannot recover consciousness."

Annas considers this bad medicine and bad law.

The President's Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioral Research [1983] views withdrawing intravenous fluid as ethically acceptable when it is more burdensome than beneficial from the patient's point of view. This point of view of the patient is made by the decision maker determining what would be of benefit to the patient in the event the patient's wishes are unknown or utilizing the patient's expressed wishes [The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983]. As for the legal side of this issue, it has been deemed acceptable to withdraw artificial hydration when, from the patient's point of view, the burdens outweigh the benefits [Annas, 1985; Matter of Conroy, 1983]. According to the American Academy of Neurology [1989],



"The artificial provision of nutrition and hydration is a form of medical treatment and may be discontinued in accordance with the principles and practices governing the withholding and withdrawal of other forms of medical treatment. It is good medical practice to initiate the artificial provision of fluids and nutrition when the patient's prognosis is uncertain, and to allow for the termination of treatment at a later date when the patient's condition becomes hopeless."

Once the decision to remove artificial hydration has been made, the comfort of terminal patients can be provided by various supportive measures. These include relieving dry mouth and throat with crushed ice or sips of fluid and nausea can be alleviated with antiemetic medication [McCann, Hall, & Groth-Juncker, 1994; Printz, 1988]. But what are the symptoms of fluid deprivation in a terminally ill patient? A reduction in fluid significant enough to produce hypovolemia causes the blood urea nitrogen level to rise due to renal hypoperfusion [Printz, 1988]. Tissue perfusion eventually deteriorates and lactic acidosis occurs once hypovolemia advances to the extreme state; hyperkalemia develops from the acute acidosis and kidney failure [Printz, 1988].

The laboratory data of a dying patient not receiving artificial hydration are

easier to evaluate than the patient's symptoms. The symptoms vary ranging from no distress to lethargy, weakness, dry mouth, thirst, restlessness, and nausea with weakness and dry mouth most typically reported [Billings, 1985; Oliver, 1984]. Dry mouth can be relieved with sips of cold water or having the patient suck on chips of ice; patients experiencing weakness should be left untreated since it is not a problem to patients left in this state [Derr, 1986].

Hydration in the terminally ill patient often increases urinary output which increases the need for an indwelling catheter, exposing the patient to infections [Rousseau, 1992]. It can also increase pharyngeal and pulmonary secretions, inducing cough, dyspnea, and pulmonary edema [Rousseau, 1992]. In a study by McCann, Hall, and Groth-Juncker [1994], the lack of fluid intake also generally produced the positive effects of decreased secretions, as shown by a reduction in episodes of prolonged choking and the infrequent need for suctioning in their patients. Nausea and vomiting, especially in patients with intestinal neoplasms or strictures, will be exacerbated by the increase in gastrointestinal fluids [Rousseau, 1992]. On the other hand, urine output will be limited with fluid deprivation, eliminating the need for urinals and catheterization [Rousseau, 1992]. Cough and congestion will be improved due to diminished pulmonary secretions; nausea and vomiting will be reduced given the reduction in intestinal secretions [Rousseau, 1992].

Over the past fifteen years, legal cases involving the right to refuse

life-sustaining treatments have increased [Wall, et al., 1991]. In June, 1990, the U.S. Supreme Court decided for the first time, a case involving a patient's right to refuse medical treatment. In *Cruzan v Missouri Department of Health*, in a 5 to 4 decision, the US Supreme Court upheld a state's constitutional right to protect and preserve human life. In denying the Cruzan's request because they had not "clearly and convincingly shown that their daughter would have wanted the treatment stopped", the U.S. Supreme Court upheld a state's privilege to preserve human life, but also affirmed an individual's right to decline life-prolonging procedures [Wall, et al., 1991].

In reviewing the Cruzan case, the U.S. Supreme Court did not distinguish between the provision of food and water and other forms of life-sustaining treatment, such as surgical intervention and mechanical assistance with breathing. This interpretation differs from the traditional division of life-support systems into ordinary care, such as intravenous fluid, food and water, and extraordinary care, such as respirators and dialysis machines. In earlier cases, providing ordinary care was considered mandatory and extraordinary care was considered optional [Wall, et al., 1991].

The courts have established that competent individuals have the right to reject treatment, including artificial feeding [Annas, 1986]. This privilege to self-determination and power over medical decisions is shielded by the due process clause of the 14th Amendment of the United States Constitution [Annas,

1986]. For incompetent patients, family members and caretakers should try to establish the patient's desires; however, establishing what is "clear and convincing evidence" of incompetent patients is difficult [Lo & Steinbrook, 1991]. The use of advance directives and patient-appointed surrogates will help "determine the clear and convincing standard in an operational manner" [Lo & Steinbrook, 1991].

The decision to either withhold or withdraw or initiate hydration in the terminally ill should be discussed with the health care team as well as the patient's family members, and should be one of empathy and compassion [Siegler & Weisbard, 1985]. The primary goal of treatment for the terminally ill patient should be changed from cure or control of the disease to keeping the patient comfortable [Siegler & Wiesbard, 1985]. Emotional support and solace should be furnished continuously by the professional health care staff to both patient and family members, through verbal and nonverbal communication [Boisaubin, 1984]. While moral and ethical opinions of health care providers warrant acknowledgment, they are generally secondary to those of the patient and the patient's family concerning the right to provide or to deny consent for life-sustaining treatment [American Academy of Neurology, 1989].

### Dietitians' Role in Feeding the Terminally Ill

Although medical, legal, and bioethical discussions have focused on withholding or withdrawing food and fluid from individuals who are terminally ill

or in a persistent vegetative state, few discussions have considered the role of the dietitians or how dietitians perceive their role [Wall, et al, 1991]. The American Dietetic Association published a position paper on feeding the terminally ill individual which includes guidelines for determining appropriate levels of nutritional care and proposes an active role for the dietitian in developing feeding criteria and in decision making. According to the American Dietetic Association, the primary consideration in assessing a patient's nutritional care is that each case be handled individually [King & Maillet, 1992]. It may be easier for dietitians to disagree or agree with abstract concepts for initiating or discontinuing nourishment than to actually apply these concepts in real-life situations. Health care goals need to be consistent with patients' expressed wishes. The dietitian needs to keep in mind that the patient's right to self-determination is utmost and the desire to forgo nutrition does not mean professional failure.

The American Dietetic Association's 1992 guidelines for feeding the terminally ill and the 1990 Supreme Court decision for an individual to refuse life-prolonging procedures, may help dietitians to assess complicated situations concerning feeding and nonfeeding patients or residents. In 1986, the Council on Ethical and Judicial Affairs of the American Medical Association included nutrition in a list of life-prolonging medical treatments that can be withheld [Wall, et al, 1991]. The Council also stated that all means of life-prolonging treatment

can be discontinued in irreversibly comatose patients, even when death is not imminent [Wall, et al., 1991].

The incompetent individual presents special legal considerations, particularly in states with strict regulations governing the discontinuation of different types of treatment. Because the U.S. Supreme Court upheld a state's right to require clear instruction from competent individuals, dietitians should encourage patients to discuss their preferences with their physician and family members, and especially to complete living wills [Wall, et al. 1991]. These advance directives enable a patient's wishes to be honored and help family members and friends to confidently act in the patient's best interest. Successful application of the American Dietetic Association guidelines will take practice due to the emotional controversy surrounding the right to decline life-prolonging treatments. Dietitians are appropriate participants in these bioethical decisions [Wall, et al, 1991].

## Chapter 3

### Methodology

#### Subjects

Subjects were registered dietitians employed in the United States by the Marriott Management Services, a division of Marriott Corporation, Inc. working in the clinical field. Registered dietitians' names and work addresses were obtained from Human Resource Managers of the Marriott Corporation after receiving written permission from the Vice President of Human Resources [See Appendix A].

#### Instrumentation

Of the 763 registered dietitians employed by the Marriott Corporation, 414 were sent the questionnaire with a cover letter and subject's permission form through the mail [Appendix B, C, and D]. Approval to conduct the study was obtained from the Institutional Review Board for Studies involving Human Subjects of Virginia Polytechnic Institute and State University, Blacksburg, Virginia. This instrument was appropriate because the sample was geographically spread out throughout the United States. In addition, a mail questionnaire was more cost-effective than face-to-face interviews or telephone surveys with respect to financial resources and research personnel. Information was obtained regarding age, sex, marital status, and education level of the registered dietitians. These questions were asked because life experiences can

have an influence on the responses to the questions in the questionnaire. However, respondents had the option to refuse to answer these questions, and were informed of this in the cover letter [See Appendix C]. Most of the questions were developed by the main author based on her own experience with long term care residents and the use of advance directives and living wills in nursing home settings. Question 6 "An advance directive and living will will decrease family conflict over decisions to withhold treatments" and Question 9 "Prolonging life is more important than honoring a patient's request to withhold 'heroic' treatment." came from an article by Davidson et al [1989]. All the responses remained confidential.

The questionnaire mailing included a letter of invitation to the subjects asking them to give their opinion regarding withholding and/or withdrawing food and/or fluid in the terminally ill individual [Appendix C]. Questions that were asked of the registered dietitians varied and covered areas such as: competent patients refusing life-sustaining treatment (ie. artificial hydration and nutrition) and rights of competent patients in making value judgments concerning their health and medical treatments, whether competent patients have the right to their medical information, and the differences between competent, elderly, terminally ill patients and competent, young, terminally ill individuals. Other questions included physicians' role in decision-making treatments of terminally ill patients, the use of advance directives and living wills, and treatments for



incompetent patients involving artificial hydration and nutrition. [See Appendix B].

### Data Analyses

The registered dietitians who received the questionnaire were asked to indicate their agreement or lack of agreement with thirteen statements about patient autonomy, advance directives, and living wills, using a 3-point Likert-type scale (agree, neither agree nor disagree, and disagree). Statements were scored from 1 to 3, with higher scores reflecting a more favorable attitude toward patient autonomy, advance directives, and living wills.

Data obtained from the surveyed registered dietitians were tabulated and analyzed using the analysis of variance (ANOVA) to determine where there were differences between and among the responses of the registered dietitians. The responses were also studied using ANOVA to determine the effects of each variable separately as well as the interaction between the variables.

## Chapter 4

### Results & Discussion

#### Response Rate

There were 763 registered dietitians employed by the Marriott Management Services Division of the Marriott Corporation, Inc. at the time this survey was conducted between July, 1994 and July, 1995. Only 414 registered dietitians were sent the questionnaire, and of the 414 dietitians sent the survey, 284 responded [69%]. This relatively high response rate may be due in part to the challenge registered dietitians are facing with the termination of nutritional support in terminally ill individuals. Also, this group of individuals surveyed were a highly motivated group of professionals who shared a great deal of interest in this demanding aspect of their job. Responses were analyzed using frequency distribution; results are indicated in Table A. Respondents had the option to refuse to answer questions regarding age, gender, marital status, and educational level; therefore, the total number of respondents for these question will not always total up to 284.

#### Description of Respondents

The demographic questions were developed because life experiences can have an influence on the responses to the questions in the questionnaire. Information was obtained regarding age, sex, marital status, and education level of the registered dietitians. For those that responded, 278 were female [98

percent]. This sample was representative of the American Dietetic Association [ADA] in terms of gender, since 97 percent of the ADA members are female [Wall, et al.,]. Most of the respondents were under 40 years of age [227 individuals (80 percent)]. Approximately one-third of the respondents [87 individuals] had a Master's degree. A little more than two-thirds of the respondents [182 individuals (68 percent)] were married.

Table A: Demographic Characteristics of Respondents

| Characteristics        | Frequency | Percent | Frequency Missing |
|------------------------|-----------|---------|-------------------|
| <b>AGE:</b>            |           |         |                   |
| 20 - 29                | 94        | 36      |                   |
| 30 - 39                | 115       | 44      | 22                |
| 40 - 49                | 40        | 15      |                   |
| 50 +                   | 13        | 5       |                   |
| <b>GENDER:</b>         |           |         |                   |
| Female                 | 272       | 98      | 7                 |
| Male                   | 5         | 2       |                   |
| <b>MARITAL STATUS:</b> |           |         |                   |
| Single                 | 69        | 26      | 16                |
| Married                | 182       | 68      |                   |
| Widowed                | 16        | 6       |                   |
| Divorced               | 1         | 0.4     |                   |
| <b>DEGREE:</b>         |           |         |                   |
| Bachelor's             | 186       | 68      | 9                 |
| Master's               | 87        | 32      |                   |
| Doctoral               | 2         | 0.7     |                   |

## Dietitians' Attitudes Regarding Withholding and/or Withdrawing Food/Fluid

This questionnaire provided an opportunity for the respondents to share their attitudes with respect to this very controversial situation. Respondents were instructed to share their opinions honestly, regardless of professional guidelines, institutional policies or legal requirements. It is important to note that the scale used was a three-point scale, with 1 equal to strongly disagree, 3 equal to neither disagree nor agree, and 5 equal to strongly agree.

Without breaking down the results into the different variables, the majority [275 respondents (99 percent)] strongly agreed that competent terminally ill individuals had the right to refuse life-sustaining treatments, and 99 percent [282 respondents] strongly agreed that competent patients should have information about their medical condition. With respect to this area of concern, 281 respondents [99 percent] strongly agreed that competent, terminally ill patients should have the right to make value judgments concerning their health and medical treatments, and 260 respondents [92 percent] strongly agreed that patients should discuss their preferences of medical treatments with their family and close friends. Similarly, 196 respondents [71 percent] strongly disagreed that any family member of incompetent, terminally ill patients can make the decisions regarding life-sustaining medical treatments. More than half of the respondents [169 individuals (61 percent)] strongly disagreed, whereas 81 respondents [29 percent] strongly agreed that withdrawing food/fluid is the same

as other medical treatment. Most of the respondents [218 individuals (77 percent)] strongly agreed that physicians should discuss treatments with their patients prior to the development of a terminal condition, and in the event a patient does develop a terminal condition, 251 respondents [89 percent ] strongly disagreed that the physician should discuss the situation with the family instead of the patient.

When asked if prolonging life is more important than honoring a patient's request to withhold medical treatment, 262 respondents [94 percent] strongly disagreed, and 259 respondents [93 percent] strongly disagreed that once a feeding tube is inserted it can never be removed until the patient is deceased. The majority of the respondents [272 individuals (96 percent)] strongly agreed that a competent, elderly terminally ill patient has the same right to refuse life-sustaining medical treatment as a young, healthy competent individual. The majority of the respondents [230 individuals [82 percent]] strongly agreed that a patient having advance directives or living wills will decrease conflict between families and the decision to withhold or withdraw food and/or fluid from the terminally ill individual, and 249 respondents [81 percent] strongly agreed that every one should have an advance directive and living will .

When the questionnaire was broken down according to the different variables identified [age, gender, marital status, and educational level], the Chi Square method showed no significant statistical differences between the

different variables identified. There is no table representing percentage of respondents according to gender since only two percent were male. The sums were not statistically significant when broken down according to age, marital status, and degree of education. Question 4 is the only exception, which showed only a marginal difference between the variables studied. Analysis of Variance [ANOVA] compared the new sum across the three age groups and found no statistically significant difference  $F(2,231)=0.48, p>.5$ . One-way Analysis of Variance found no significant difference for the total questionnaire score when broken down by respondents degree or the level of education  $F(2,240)=0.19, p>.5$ . Refer to Tables B, C, and D for results.

Table B: Percentage of respondents according to age\*

| Questions   | AGES 20-29        |         |                | AGES 30-39        |         |                | AGES 40-49        |         |                | AGES 50+          |         |                |
|---|-------------------|---------|----------------|-------------------|---------|----------------|-------------------|---------|----------------|-------------------|---------|----------------|
|   | Strongly Disagree | Neither | Strongly Agree | Strongly Disagree | Neither | Strongly Agree | Strongly Disagree | Neither | Strongly Agree | Strongly Disagree | Neither | Strongly Agree |
| 1. Competent patients have a right to refuse life-sustaining treatment.   |                   | 9       | 27             |                   |         | 43             | 1                 |         | 14             |                   |         | 6              |
| 2. Competent patients should have information about their medical condition.  |                   |         | 36             |                   |         | 44             |                   |         | 14             |                   |         | 5              |
| 3. Withdrawing food/fluid is the same as withdrawing other forms of medical treatment.  | 8                 | 5       | 23             | 13                | 6       | 25             | 3                 |         | 10             | 2                 | 1       | 2              |
| 4. Physicians should discuss the use of life-sustaining treatments with all their patients before a terminal condition occurs.                            | 2                 | 4       | 30             | 2                 | 9       | 33             | 1                 | 2       | 12             |                   |         | 4              |
| 5. Physicians should discuss medical information and decisions with the families of competent terminally ill patients instead of the patients themselves. | 32                | 3       |                | 40                | 2       | 1              | 14                | 1       |                | 4                 | 1       |                |
| 6. Advance directives/living wills will decrease family conflict over decisions to withhold treatments.   | 1                 | 6       | 28             | 2                 | 5       | 36             | 1                 | 2       | 13             |                   |         | 5              |
| 7. Patients should discuss their preference of medical treatment with their family and close friends.   | 1                 | 2       | 33             |                   | 2       | 41             |                   |         | 15             |                   |         | 5              |
| 8. Competent terminally ill patients should have the right to make value judgments concerning their health and medical treatments.                        | 1                 |         | 34             |                   |         | 44             |                   |         | 16             |                   |         | 5              |
| 9. Prolonging life is more important than honoring a patient's request to withhold medical treatment.   | 33                | 3       |                | 41                | 2       |                | 11                |         |                | 5                 |         |                |
| 10. Competent, elderly, terminally ill patients have the same right to refuse life-sustaining treatments as young, healthy, competent individuals.        |                   |         | 36             | 1                 |         | 42             |                   | 1       | 15             | 1                 |         | 4              |
| 11. A feeding tube can never be removed until the patient dies.   | 33                | 3       |                | 42                | 1       | 1              | 14                |         |                | 4                 | 1       |                |
| 12. Any family member of incompetent patients should make the decisions regarding life-sustaining treatments.   | 26                | 5       | 6              | 29                | 8       | 7              | 12                | 2       | 1              | 3                 | 1       | 1              |
| 13. Everyone should have a living will and an advance directive.  |                   | 4       | 33             | 1                 | 4       | 39             | 1                 | 1       | 15             |                   |         | 5              |

\*Totals may not add up to 100% due to respondents not answering the questionnaire completely.



Table C: Percentage of respondents according to degree\*#

| Questions   | Bachelor of Science |         |                | Masters'          |         |                |
|---|---------------------|---------|----------------|-------------------|---------|----------------|
|   | Strongly Disagree   | Neither | Strongly Agree | Strongly Disagree | Neither | Strongly Agree |
| 1. Competent patients have a right to refuse life-sustaining treatment.   | 1                   | 1       | 67             |                   |         | 30             |
| 2. Competent patients should have information about their medical condition.  |                     |         | 68             |                   |         | 32             |
| 3. Withdrawing food/fluid is the same as withdrawing other forms of medical treatment.  | 19                  | 9       | 40             | 9                 | 3       | 19             |
| 4. Physicians should discuss the use of life-sustaining treatments with all their patients before a terminal condition occurs.                            | 4                   | 11      | 52             | 2                 | 5       | 25             |
| 5. Physicians should discuss medical information and decisions with the families of competent terminally ill patients instead of the patients themselves. | 61                  | 5       | 2              | 27                | 3       | 1              |
| 6. Advance directives/living wills will decrease family conflict over decisions to withhold treatments.   | 5                   | 7       | 56             | 2                 | 6       | 25             |
| 7. Patients should discuss their preference of medical treatment with their family and close friends.   | 1                   | 3       | 64             |                   | 2       | 29             |
| 8. Competent terminally ill patients should have the right to make value judgments concerning their health and medical treatments.                        |                     |         | 68             |                   |         | 32             |
| 9. Prolonging life is more important than honoring a patient's request to withhold medical treatment.   | 65                  | 3       | 1              | 30                | 1       |                |
| 10. Competent, elderly, terminally ill patients have the same right to refuse life-sustaining treatments as young, healthy, competent individuals.        |                     |         | 66             | 1                 |         | 30             |
| 11. A feeding tube can never be removed until the patient dies.   | 62                  | 4       | 2              | 30                | 1       |                |
| 12. Any family member of incompetent patients should make the decisions regarding life-sustaining treatments.   | 49                  | 10      | 10             | 20                | 6       | 6              |
| 13. Everyone should have a living will and an advance directive.  | 1                   | 4       | 62             |                   | 4       | 26             |

\*Totals may not add up to 100% due to respondents not answering the questionnaire completely.

#There was not enough respondents with Doctorate degrees

Table D: Percentage of respondents according to marital status\*

| Questions  | Single            |         |                | Married           |         |                | Divorced/Widowed  |         |                |
|--|-------------------|---------|----------------|-------------------|---------|----------------|-------------------|---------|----------------|
|  | Strongly Disagree | Neither | Strongly Agree | Strongly Disagree | Neither | Strongly Agree | Strongly Disagree | Neither | Strongly Agree |
| 1. Competent patients have a right to refuse life-sustaining treatment.  |                   |         | 26             | 1                 | 1       | 66             |                   |         | 6              |
| 2. Competent patients should have information about their medical condition.   |                   |         | 26             |                   |         | 68             |                   |         | 6              |
| 3. Withdrawing food/fluid is the same as withdrawing other forms of medical treatment  | 7                 | 3       | 17             | 18                | 8       | 41             | 4                 |         | 2              |
| 4. Physicians should discuss the use of life-sustaining treatments with all their patients before a terminal condition occurs.                           | 4                 | 2       | 22             | 36                | 14      | 51             |                   |         | 6              |
| 5. Physicians should discuss medical information and decisions with the families of competent terminally ill patients instead of the patients themselves | 23                | 3       |                | 51                | 4       | 3              | 6                 |         |                |
| 6. Advance directives/living wills will decrease family conflict over decisions to withhold treatments.  | 2                 | 4       | 21             | 2                 | 7       | 58             | 2                 |         | 5              |
| 7. Patients should discuss their preference of medical treatment with their family and close friends.  |                   | 1       | 25             | 1                 | 5       | 62             |                   |         | 6              |
| 8. Competent terminally ill patients should have the right to make value judgments concerning their health and medical treatments.                       |                   |         | 26             | 1                 |         | 67             |                   |         | 7              |
| 9. Prolonging life is more important than honoring a patient's request to withhold medical treatment.  | 25                |         |                | 62                | 4       | 1              | 7                 |         |                |
| 10. Competent, elderly, terminally ill patients have the same right to refuse life-sustaining treatments as young, healthy, competent individuals.       |                   |         | 24             | 1                 | 1       | 66             |                   |         | 7              |
| 11. Feeding tubes can never be removed until the patient dies.   | 24                | 1       | 1              | 62                | 4       | 1              | 5                 |         |                |
| 12. Any family member of incompetent patients should make the decisions regarding life-sustaining treatments.  | 16                | 4       | 6              | 48                | 11      | 7              | 6                 |         |                |
| 13. Everyone should have a living will and an advance directive.   |                   | 3       | 23             | 2                 | 5       | 60             |                   |         | 6              |

\*Totals may not add up to 100% due to respondents not answering the questionnaire completely.

## Chapter 5

### Conclusion

The Patient-Self Determination Act of 1990 has been in effect since December 1, 1991. All hospitals, nursing facilities, home health care agencies, hospices, and health maintenance organizations participating in Medicare and Medicaid are required to ask patients upon admission questions about advance directives. The penalty for noncompliance could result in a facility's loss of eligibility to participate in Medicare or Medicaid. As defined under the Act, an advance directive is a written instrument, recognized under state law that is executed by a competent adult relating to provision of health care if and when the person becomes incompetent and unable to make decisions. The recently implemented Patient-Self Determination Act and the Cruzan Decision, among other court cases, highlight the growing importance of advance directives in our aging society. Although the medical, ethical, legal, and emotional issues surrounding decisions to withhold nutrition and hydration are complex, incorporating the wishes of nursing home residents into the care planning process may lead to more appropriate cost-effective and humane care. Advance directives will increasingly become an integral part of caring for the geriatric population.

While much attention has been focused on the opinions of physicians and nurses regarding the withholding and withdrawing of food and hydration from

terminally ill individuals, little has been written about the opinions of registered dietitians regarding this issue. This study focused on dietitians' opinions regarding these matters. A questionnaire was developed to measure the opinions of registered dietitians pertaining to withholding and withdrawing food and fluid in the terminally ill individuals. This questionnaire was sent to 414 registered dietitians employed by the Marriott Management Services Division of the Marriott Corporation, Inc.. Of the 414 questionnaires mailed out, 284 responded [69%], and the results were tabulated. Ninety-eight percent of the dietitians were female. Most [80%] were aged 39 years old or less. The majority held bachelor's degrees [68%]. Sixty-eight percent were married. The majority of the respondents [99%] strongly agreed that competent terminally ill individuals had the right to refuse life-sustaining treatments and that competent patients should have information about their medical condition. The majority of the respondents [99%] strongly agreed that competent, terminally ill patients should have the right to make value judgments concerning their health and medical treatments, and that patients should discuss their preferences of medical treatments with their family and close friends. With regard to withdrawing food and fluid being the same as other medical treatment, there was a mixed opinion among the dietitians surveyed. Sixty-one percent strongly disagreed whereas 29% strongly agreed with this question.

In general, the dietitians who responded to this questionnaire strongly

believed that the terminally ill individual and not the doctor or family members have the right to make medical decisions pertaining to his or her own health condition. This survey reaffirmed our hypothesis that registered dietitians with experience in dealing with advance directives and living wills had a more positive attitude toward dealing with the terminally ill.

The dietitian can add to the comfort of the patient by ensuring good nutritional health for as long as possible and can play an essential part in planning nutritional support with the health care team for the still responsive patient, and by helping the family make the best medical and moral decision when the patient is unresponsive. The main consideration for a dietitian when evaluating an individual's nutritional care is to handle each case on an individual basis. Older dietitians were more likely to support a patient's request to discontinue feeding than the young dietitians due partly because the young dietitians are more aggressive and idealistic in their views of nutritional therapy. The older dietitians who have acquired more experience may have recognized the deteriorating quality of life of a terminally ill individual. A dietitian needs to develop health care goals that are consistent and match the patient's expressed wishes and not to force his or her own beliefs on the terminally ill patient. The patient's right to self-determination is important and the dietitian needs to understand that if a patient refuses to accept artificial nutrition or hydration, it does not mean that the dietitian failed in any way.

In caring for terminally ill or chronically ill patients, the initiation of tube feedings are often performed to alleviate the anxiety of caregivers and families of patients or residents [Norberg, Norberg, Gippert, & Bexell, 1980]. Patients who are capable of making decisions usually refuse artificial nutrition when they are close to death or severely debilitated with little hope of recovery [Lo, Mcleod, & Saika, 1986]. The family needs to have the goals of feeding and therapy discussed to avoid misdirection in providing comfort care to the patient or resident [McCann, Hall, & Groth-Juncker, 1994]. Providing food and fluids only as needed to relieve the patient's discomfort can be an effective means of fulfilling a patient's wish while alleviating discomfort. Caregiver time can be spent providing comfort care for the patient rather than implementing artificial food and fluid.

Because of the legal, moral, and ethical issues involved with nutritional support in life-prolonging situations, Universities need to address these issues as part of the future dietitians' curriculum. In addition, strong emphasis should be placed on quality of life, patient competence and autonomy, different types of feeding options, and the dietitian's role in decision making, as well as case studies which illustrate the varying, yet commonly encountered, situations. Successful application of the American Dietetic Association guidelines in various situations will take practice because of the emotional controversy surrounding the right to die; i.e., the right to refuse life-prolonging procedures;

therefore making dietitians necessary members of the healthcare team in such bioethical decisions [Wall, et al., 1991].

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APPENDIX A  
COVER LETTER

Dear Clinical Dietitian:

The terminally ill individual has a right to be a dominant force in selecting which level of treatment and care he or she receives. Appropriate, comprehensive, yet compassionate treatment of the terminally ill patient is difficult and requires the medical team be especially sensitive to the patient's physical and emotional needs. As part of the health care team, you, as the dietitian, have an obligation to meet the physiological and psychological needs and desires of each patient on an individual basis. The purpose of this research is to investigate the opinions and attitudes of Registered Dietitians on the issues involved in the withholding or withdrawing of food and/or fluid in the terminally ill individual.

You are being asked to give your opinion on these matters. All Marriott dietitians in the United States working in the clinical setting are being sent this questionnaire, and your responses are very important to this study. Enclosed you will find a letter of consent from John Stevenson, Vice President, Human Resources, Marriott Management Services. You do not have to answer the questions about your age, educational level, marital status, sex or race, and are free to leave any question blank; however, your responses to these questions are most beneficial to this study.

It should only take no more than 15 to 30 minutes of your time to complete the 13 questions. The possible risks to you as a participant are minimal in that the results will be kept strictly confidential. At no time with the researchers release the results of the study to anyone other than the individuals working on the project without your written consent. The questionnaire has an identification number for mailing purposes only. This is so we may check your name off the mailing list when your questionnaire is returned. Your name will never be placed on the questionnaire. The authors of this study - Drs. S. J. Ritchey, E. D. Schlenker, and C. Rogers, and myself - will be the only ones who have access to the data.

You may receive a summary of the results by enclosing a self-addressed envelope. Please **do not** put this information on the questionnaire itself. I do appreciate you taking time out of your busy schedule to answer this questionnaire.

Sincerely,

Karen Dietrich, R.D., L. D.

APPENDIX B  
QUESTIONNAIRE

## QUESTIONNAIRE

Please circle each question according to how you agree

AGE: \_\_\_\_\_ SEX: \_\_\_\_\_

EDUCATION :                      BS                      MS                      PHD

MARITAL STATUS:                      Single                      Married                      Divorced                      Widowed

| Questions   | Strongly Disagree | Neither | Strongly Agree |
|---|-------------------|---------|----------------|
| 1. Competent patients have a right to refuse life-sustaining treatment.   | 1                 | 3       | 5              |
| 2. Competent patients should have information about their medical condition.  | 1                 | 3       | 5              |
| 3. Withdrawing food/fluid is the same as withdrawing other forms of medical treatment.  | 1                 | 3       | 5              |
| 4. Physicians should discuss the use of life-sustaining treatments with all their patients before a terminal condition occurs.                            | 1                 | 3       | 5              |
| 5. Physicians should discuss medical information and decisions with the families of competent terminally ill patients instead of the patients themselves. | 1                 | 3       | 5              |
| 6. Advance directives/living wills will decrease family conflict over decisions to withhold treatments.   | 1                 | 3       | 5              |
| 7. Patients should discuss their preference of medical treatment with their family and close friends.   | 1                 | 3       | 5              |
| 8. Competent terminally ill patients should have the right to make value judgments concerning their health and medical treatments.                        | 1                 | 3       | 5              |
| 9. Prolonging life is more important than honoring a patient's request to withhold medical treatment.   | 1                 | 3       | 5              |
| 10. Competent, elderly, terminally ill patients have the same right to refuse life-sustaining treatments as young, healthy, competent individuals.        | 1                 | 3       | 5              |
| 11. A feeding tube can never be removed until the patient dies.   | 1                 | 3       | 5              |
| 12. Any family member of incompetent patients should make the decisions regarding life-sustaining treatments.   | 1                 | 3       | 5              |
| 13. Everyone should have a living will and an advance directive.  | 1                 | 3       | 5              |



**APPENDIX C**  
**SUBJECT'S PERMISSION**

### SUBJECT'S PERMISSION

I have read and understand the informed consent and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent for participation in this project.

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Signature

Should I have any questions about this research or its conduct, I will contact:

Karen Dietrich, R.D., L.D. [410] 968-1200 ext. 3215

Dr. S. J. Ritchey, PhD., R.D. [540] 231- 4672

Ernest Stout, Chair [540] 231 - 6077  
Institutional Review Board

Tear off here and keep above for your records

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Return bottom with questionnaire

### SUBJECT'S PERMISSION

I have read and understand the informed consent and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent for participation in this project.

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Signature

**APPENDIX D**

**APPROVAL LETTER FROM  
MARRIOTT MANAGEMENT SERVICES**

**Marriott**

Marriott Management Services  
Health Care

100 Avon Meadow  
Avon, CT 06001

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John Stephenson  
Vice President, Human Resources  
203/678-1023  
203/676-0798 Fax

To Whom It May Concern:

Marriott International, Inc., Health Care Services Division, gives approval for Karen Dietrich to survey Marriotts' Clinical Dietitians as part of her thesis with Virginia Polytech Institute and State University.

Sincerely,



John Stephenson  
Vice President, Human Resources

177

## VITA

Karen Dietrich earned a Bachelor of Science degree in Nutrition from Virginia Polytechnic Institute and State University in 1986. She worked as a Public Health Nutritionist before applying for a Master of Science degree in Nutrition from VPI & SU in 1988. She applied for the Coordinated Program in Dietetics in 1990 from VPI & SU. She is currently employed by Marriott Management Health Care Services.

*Karen Dietrich*

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