NUTRITIONAL SUPPORT FOR THE TERMINALLY ILL PATIENT: ATTITUDES AND ETHICS EDUCATION OF DIETITIANS

by

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(ABSTRACT)

This study was conducted to investigate attitudes of dietitians regarding ethical dilemmas surrounding nutritional support for terminally ill patients. In addition, the methods and adequacy of ethics training received in dietetics education and in supervised experience programs, such as the Approved Preprofessional Practice Program (AP4), Coordinated Program in Dietetics (CPD), dietetic internship (DI), or any other experience approved by the American Dietetic Association (ADA), was researched.

A mailed questionnaire was sent to 147 dietitians living in Virginia with one to three years of clinical experience. Of the 144 deliverable questionnaires, 104 (72.2%) were returned, and results were tabulated. Data analysis included descriptive analyses, Pearson's correlation coefficient tests and analysis of variance (ANOVA) of selected variables.

Results indicated that the majority of the dietitians surveyed were women younger than 40 years old who reasoned contextually in decisions regarding termination of nutritional support, had little or no formal ethics education, and held

either bachelor's or master's degrees. Dietitians who felt more confident with making ethical decisions were significantly more contextually influenced in nutritional support decisions than those who were somewhat, or not at all, confident. Those who said they brought spiritual beliefs to bear to a great extent in ethical decision-making used more absolute principles in their decision-making. There were no differences in attitudes or ethics training relative to which supervised experience was completed, or to the highest degree attained.

Most dietitians have not had formal ethics training, and they are not confident in ethical decision-making. Therefore, dietetics education may need to focus on ethics training to enable future dietitians to effectively deal with ethical dilemmas they will face in their professional lives.

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And finally, this thesis is dedicated to my parents, Maureen Lyons Fletcher and Ronald Stephen Knapp, and to Roger Edward Tillett, with continuing love and gratitude.

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Chapter 1

Introduction

Issues of professional ethics are attracting a great deal of attention in business, government, education, and medicine. With the explosive growth of medical technology, rising health costs, and an increasing emphasis on patients' rights to self-determination, the health care community recognizes the need for its involvement in moral and ethical decisions. Professional codes relative to health care are designed to provide guidelines in making ethical decisions, and to protect the health, safety, and welfare of the public. An increase in the number of ethics committees in clinical settings, led by trained ethicists, provides an opportunity for health care professionals to discuss ethical issues and determine the most morally desirable action when faced with conflicting value choices.

Life-sustaining technology raises many ethical questions pertaining to withdrawing or withholding a patient's treatment, especially for the terminally ill patient. Dietetic professionals face ethical issues in practice that relate to all facets of patient care. Today, nutritional support, used to sustain life, may be considered, by some, extraordinary life support which may be withdrawn or withheld from patients. Since the resolution of these ethical dilemmas affects health care professionals, the public, and the particular patient, it must involve the patient, the patient's family, and each member of the health care team, including the dietitian.

Ethics education and training might, indeed, assist health care professionals

in ethical decision-making. A lack of education in this area may promote personal detachment from ethical dilemmas and prevent moral growth in professionals (Neville and Chernoff, 1988). This instruction should begin in the dietetic education programs prior to exposure to the clinical setting, such as a hospital (Anderson, 1991). University educators of student dietitians should be addressing ethical issues in the classroom and allowing open discussion among the students. This opportunity would allow dietitians to develop and understand their own ethical principles before making decisions in a work setting.

Though, in general, dietetic students are aware of ethical concerns, their level of education and guidance in this subject may be inadequate. This study was designed to assess the ethical attitudes and beliefs of dietitians in Virginia with one to three years of clinical experience, concerning nutritional care of terminally ill patients. In addition, the study ascertained when ethics education is taught to the dietetic student and the educational setting under which this training is administered. Finally, the adequacy of the training received was determined. This information will help to define the educational needs of future students and indicate specific areas requiring improvement.

Justification

Because study findings indicated that ethics education in the dietetic curriculum is limited, further research is necessary in order to determine how ethics education is taught to dietetic students in academic programs (Luby et al., 1991).

The attitudes and beliefs of dietitians concerning nutritional care of terminally ill patients was determined to pinpoint the need for further ethics training in dietetics education in academic and American Dietetic Association (ADA) approved supervised experience programs (ie. dietetic internship (DI), Approved Preprofessional Practice Program (AP4), Coordinated Program in Dietetics (CPD)).

Obviously, the beginning of the dietitian's career in the clinical setting will provide many opportunities for reflection on ethical issues and moral growth, though this may not be the most appropriate environment in which to begin to examine personal moral principles. Ethics education should begin in the classroom and should be integral to the supervised experience program to facilitate the growth process. Role-playing, case studies, exposure to legal decisions regarding health care, and open classroom discussions are invaluable modes of stimulating critical thinking skills (Luby et al., 1991).

Objectives

The researcher had the following objectives:

1. To determine the attitudes and beliefs of dietitians in Virginia with one to three years of clinical experience, about nutritional support of terminally ill patients.
2. To define the format and content of ethics education the dietitians received, as students.
3. To determine whether dietitians feel that their ethics training was adequate.

Chapter 2

Definition of Terms

For the purposes of this study, the following definitions will be used:

Terminal illness - the end or final stage of a specific, progressive, normally irreversible lethal disease when physicians have "determined, through objective medical validation, that medical treatment of that disease is futile" (President's Commission, 1983) and the disease will cause the patient's death in the foreseeable future (American Dietetic Association, 1992).

Nutritional support - referring to artificial feeding by enteral or parenteral means.

Ethical - pertaining to the rational processes for determining the most morally desirable course of action in the face of conflicting value choices (American Hospital Association, 1985).

Patient Competence - patients are either decisionally "competent" or "incompetent." Adults are presumed to be legally competent whether or not they have been diagnosed as terminally ill and are, thus, theoretically capable of participating in defining parameters of medical treatment for themselves. Otherwise, a formal court declaration of "incompetence" is required for this purpose (American Dietetic Association, 1992).

Comatose - referring to patients who are neither responsive nor "brain dead"; in a persistent vegetative state.

Chapter 3

Literature Review

The purpose of this review of literature is to present an overview of the concept of professional ethics and the many ethical issues which pertain to health care and, specifically, to the field of dietetics. Individual cases involving the nutritional care of terminally ill patients are summarized. In addition, research which determines dietitians' attitudes and beliefs about feeding the terminally ill is discussed. Finally, the quality of ethics education in dietetics education is reviewed.

Defining Professional Ethics

Ethics pertains to the determination of the most morally desirable action when one is faced with conflicting value choices (American Hospital Association, 1985). The ethical issues one is faced with may not be addressed by laws; they often have to do with beliefs, religions, and moral practices (Neville and Chernoff, 1988). Ethical issues pervade all professions. When considering the various aspects of health care, many possible ethical dilemmas arise. All health care professionals are involved in ethical decision-making on a regular basis, whether it be as a member of a hospital ethics committee, as a professional acting alone to make a decision which is in the best interest of the patient, or as an individual involved in personal

decision making. There are numerous ethical issues in the field of dietetics and health care, ranging from the ethical aspects of weight loss programs to the ethics of using advanced medical technology to provide life-sustaining nutriture.

Because settings for dietetics practitioners are varied, the issues faced by dietitians are diverse. In order to guide members of the American Dietetic Association in ethical decision-making, the present Code of Ethics for the Profession of Dietetics was developed (American Dietetic Association, 1988). Its function is to provide an outline of the obligations of the dietetics practitioner to self, client, society, and the profession. The present code was adopted in 1987 and published in the *Journal of the American Dietetic Association* in 1988. An outline of the guidelines presented in the code appears in Appendix A.

Anderson (1993) surveyed 341 dietetics practitioners to assess the extent to which dietitians adhere to the profession's Code of Ethics as it applies to their own practices. A mean of 75.9% of the respondents reported either "always" practicing specific components from the Code of Ethics or "strongly agreeing" with code statements, and 20.6% reported either "very often" practicing specific components from the code or "agreeing" with Code statements. It cannot be confirmed that dietitians adhere to and agree with the Code in **all** ethical situations, since specific ethical issues, such as the withdrawal of life sustaining nutriture, were not discussed in this study. The author suggested that dietetics educators should consider administering the questionnaire described above to students and discussing questions

and specific ethical issues afterwards.

Ethical Issues

Nutritional Support and the Terminally Ill Patient. Nutritional support is well accepted medically, morally, and legally and should be provided to all patients with hope of recovery. In the responsive terminal patient, nutritional support should be continued if the patient desires it and may benefit from it in some way. When health cannot be maintained or restored, and the patient is not responsive, is nutritional support always indicated? This decision must be made by the patient or by a surrogate, such as the family, if the patient is not competent, with the help of the dietitian and the entire health care team (Boisaubin, 1984).

According to the American Dietetic Association (1992), terminally ill adults have a right to be a major force in choosing which level of treatment and care they wish to receive. The dietitian, as part of the health care team, has a responsibility to meet the psychological and physiological needs and wants of each patient on an individualized basis. Generally, compassionate palliative care becomes the fundamental, realistic medical goal in caring for the terminally ill adult. Care should constantly be reassessed for each patient, since each patient is unique. The goal is to lessen pain, psychological distress, and symptoms without attempting to cure. It is important to decrease the incidence of vomiting, nausea, insomnia, and anxiety.

There is increasing professional consensus that there are circumstances in which feeding, by any means, becomes a monumental and futile task. To determine appropriate levels of nutrition care it is important to consider the patient's medical status, the patient's informed preference, and the ethical and legal framework within which feeding alternatives are considered and policies formulated. The focus of care should emphasize patient comfort. The dietitian should have an active role in developing feeding criteria and in decision making.

The denial of food and fluids is biologically "final" in a way that medical or surgical therapy is not. Although a patient may not die if certain medical or surgical therapy is not provided, it is never possible for a patient to survive without food and fluids. This denial is a sufficient and certain cause of death for any human being, though almost every human being can and does survive without renal dialysis, artificial respiratory support, antibiotics, cardiopulmonary resuscitation, mitral-valve surgery, or any of the other wonders of modern medicine (Derr, 1986). Allowing a person to starve or dehydrate to death is repugnant to many because death is believed to be caused more by a failure to be responsible to ordinary moral obligations to provide non-heroic measures to promote human life than by any other cause (Barry, 1985).

Some believe that the denial of food and fluids diminishes the integrity of the medical profession as a learned and ethical profession. Derr states that a social decision to allow physicians or health care professionals to deny food and fluids to

patients, who are capable of receiving and utilizing them, directly attacks the foundation of medicine as an ethical profession (Derr, 1986). Meilaender (1984) agrees that, if we deny food and fluids, we are withholding the nourishment that sustains all life. His argument questions how services which include turning patients regularly and giving alcohol rubs are standard nursing care when feeding is not. Also, he suggests that if feeding cannot benefit these patients, it is not clear how bed sores can harm them (Meilaender, 1984). Barry (1985) believes that the removal of food and water is a failure to provide a basic necessity of life for an individual in need. Similarly, he feels that providing foods and fluids is an ordinary moral duty because they are the means by which natural life is sustained (Barry, 1985).

The provision of food and water, or their removal, has a very meaningful symbolic content which is deeply rooted in our society (Capron, 1984). Feeding conveys caring and provides a sense of community. In addition, food symbolizes maternal nurturing, and has religious, cultural, and social values (Mishkin, 1986). Providing food and drink is basic to human relationships-it has been so throughout time and across all cultures-and so offering food and water to the vulnerable is a powerful symbol of concern and compassion (Koshuta et al., 1991).

When a dying patient is unable to tolerate feeding, it is a signal to family and caregivers that death is near. In this case, nutrition and hydration by artificial means may not carry the same symbolism as in the above case, especially in the context of anticipated death (Koshuta et al., 1991).

The dietitian may become involved in decisions to withhold nutrition and hydration as a member of the health care team that is responsible for the care of an individual patient, or as a member of an ethics committee. Many moral principles must be considered in this decision making, including benefit to patient, respect for patient autonomy or self-determination, maintenance of the moral integrity of health care professionals, and justice in distributing scarce medical resources among all eligible patients. It is helpful to approach decision processes as moral conversations rather than as the application of hard and fast dogma (Brody and Noel, 1991).

According to the American Dietetic Association (1992), the dietitian has an inherent responsibility to respect the sanctity of life and the dignity and rights of all persons and to provide relief from suffering. As a part of the health care team, the dietitian should help to educate the patient, or surrogate, on feeding options, defining associated benefits and burdens so that informed decisions can be made (Gallagher-Allred, 1989; Schiller, 1988). In order to help in the care planning for terminal patients, the dietitian should become familiar with the local legal statutes pertaining to withholding or withdrawing nutrition support, resources for services, referral criteria, and services for other team members (Capozza, 1991).

Withdrawal of Life-Sustaining Nutriture. Suffering must be distinguished from pain or other symptoms with which it may be associated. The relief of suffering is considered one of the primary goals of medicine; however, what health care

professionals must do to prevent or relieve suffering is not well understood. Today, the chronically, severely sick patient, whose life medical technology is prolonging, has an enormous potential for suffering. Often, the medical care given fails to relieve the suffering, and may even increase it (Cassell, 1983).

In an effort to relieve patients' suffering, rather than adding to it, the following question arises: When is it ethically permissible to discontinue life-sustaining medical treatment? Ramsey (1976) argues that it is reasonable to discontinue medical treatment if its continuation will affect the living person's condition in no significant respect except to prolong dying. The distinction between "ordinary" and "extraordinary" treatment may also provide guidelines in making such an ethical decision, whereby, "ordinary" is defined as treatment that is medically indicated and expected to be helpful, while "extraordinary" is treatment that is not medically indicated, is burdensome for the patient or family, and will not provide benefits to the patient (Ramsey, 1976; Cohen, 1982). This distinction is a basis for ethical decision making, since only those treatments that are classified as "ordinary" must (ethically) be provided; "extraordinary" treatments are dispensable.

Many terminally ill patients and their families request the omission of life-prolonging measures, either verbally or in signed statements. Patients may have a "do not resuscitate" (DNR) order, or they may request that advanced life support, such as hemodialysis, mechanical ventilation, and artificial nutritional support, not be used. It is difficult, though, to monitor whether or not physicians and other

health care professionals, act according to these requests. With the advanced medical technology available, decisions not to resuscitate have become increasingly complex, since many seemingly unrelated therapies are central to emergency resuscitation efforts, such as vasopressors and mechanical ventilators. This leads to confusion about the precise meaning of the "do not resuscitate" order (LaPuma et al., 1988).

Noyes et al. (1977) found that physicians' attitudes toward prolonging life in terminal patients are changing regarding communication with terminal patients and the omission of life-prolonging treatments. They found that communication with dying patients is becoming more open, and that support for the omission of life-prolonging treatments is increasing when the decision is consistent with the patient's wishes (Noyes et al., 1977). It is important to note that the patient's role in decision making is crucial; a decrease in aggressive treatment of the terminally ill patient is advisable when such treatment would only prolong a difficult and uncomfortable process of dying (Wanzer et al., 1984).

Prolongation of life, increased ability to recover from the effects of other medical treatment, and possibilities for return to useful function are all important benefits that artificial nutrition can confer to terminal patients. However, when the means of administering nutrition become invasive and painful, then the burdens may become substantial. In addition, patients may feel a loss of dignity being kept alive by artificial means. Spiritual and emotional burdens ought to be assessed along with

physical burdens in making an assessment of the benefits and burdens of nutritional support (Brody and Noel, 1991).

According to a California Court decision (1983), the benefits and burdens of nutritional support should be evaluated in the same manner as are those of any other medical procedure. In addition, the Court ruled that treatment should be evaluated according to its benefits and burdens to the patient:

> Even if a proposed course of treatment might be extremely painful or intrusive, it would still be proportionate treatment if the prognosis was for complete cure or significant improvement in the patient's condition. On the other hand, a treatment course which is only minimally painful or intrusive may nonetheless be considered disproportionate to the potential benefits if the prognosis is virtually hopeless for any significant improvement in condition.

In some cases, feeding procedures impose severe burdens on patients. When the additional life nourishment can provide is painful, or of minimal quality, it is appropriate to ask whether the burdens of continued nutrition outweigh its benefits to these patients (Dresser and Boisaubin, 1985).

One of the most basic precepts of medical ethics and law is self-determination: the right of an individual to decide his or her own destiny by

accepting or rejecting offered medical care (Beauchamp and Childress, 1979). Green (1984) agrees that since decisions about a person's best interest reflect personal value systems, the autonomous adult is the person best able to decide which among various alternative actions is compatible with cherished values. According to the American Dietetic Association (1992), the patient's expressed desire for extent of medical care is the primary guide for determining the level of nutrition intervention.

When the patient's views are known, those should be honored where medically feasible, regardless of the family's contrary views. The same is true when the patient has executed an operative directive to his physician under one of the natural death acts (Meyers, 1985). Ethical problems arise when a competent patient, not terminally ill, refuses feedings (Schiller, 1988). Traditionally, this has been considered suicide or murder (Thomasma, 1975). Thus, when a disease is not terminal, some suggest that it may be wrong for a patient or others to terminate feeding, making starvation the unambiguous cause of death (Green, 1986).

When the patient cannot choose the ideal course of treatment, a surrogate or other substitute decision maker, who is familiar with the patient's values and wishes, can act on the patient's behalf. It is important to consider, when the patient cannot speak on his or her own behalf, whether the statements the patient made regarding his or her wishes, were made at a time when the patient could envision the circumstances that now exist (Brody and Noel, 1991). The decision should ultimately be based upon whether prolonging life provides an increase in quality of life

(physiological or psychological benefit) or whether it extends the pain and suffering of the patient as well as causing a financial burden to the family (Hastings Center Report, 1987; Jernigan, 1987; Mishkin, 1986; Gallagher-Allred, 1989; American Dietetic Association, 1992).

It is standard medical practice for physicians to ask the families (or close friends) of incompetent patients to make decisions. It is generally acknowledged that families should be allowed to make decisions based on the previously expressed wishes and best interests of incompetent patients; courts should only be involved when the surrogates are not believed to be acting in good faith or when the decisions of the surrogates cannot be considered by a reasonable person to be consistent with the patient's wishes or best interests. Physicians or hospitals who challenge the family's decision must, themselves, hold responsibility for the burden of proof in court (Lo et al., 1990).

Formal written directives are preferable to oral statements when making decisions for an incompetent patient. Physicians should educate and counsel patients about treatments and situations that may commonly arise in the course of their illnesses, so that directives can be provided in advance in the event that the patient becomes incompetent. It is the responsibility of the entire health care team to keep competent patients informed about their prognosis, and the family of the patient informed in the case of the incompetent patient (Lo et al., 1990).

Cases Involving the Removal of Nutritional Support

Mary Hier. Mary Hier was a 92 year old woman who had been a resident of a psychiatric hospital in Massachusetts for 57 years; she continually pulled out her feeding tube and resisted its reinsertion. She was mentally ill and suffered from senile dementia. Mrs. Heir had no relatives who could be contacted. She suffered from a hiatal hernia and a cervical diverticulum and, therefore, was unable to take food orally. Psychotropic drugs were administered to decrease her agitation and increase her communication. The nursing home applied to the Court to appoint a guardian to consent to the administration of psychotropic drugs, and the placement of a gastrostomy tube to replace her feeding tube (Annas, 1984, 1985).

The Probate judge ruled, based on substituted judgment, that the psychotropic drugs should be administered to improve Mrs. Hier's mental state, stating that he felt that she would accept this treatment if she were competent. He found that Mrs. Hier objected to the gastrostomy tube and that placement of the tube involved high risks, due to repeated history of dislodgments. Further, he ruled that she would refuse the feeding tube, even if competent. The Appeals Court upheld this decision finding that the Probate Court's conclusion "cannot be said to have been erroneous". Mrs. Hier's guardian took the case back to the original Probate Judge and eventually was successful in getting him to reverse his position after he heard from seven additional medical witnesses; successful surgery was performed to reinsert the

gastrostomy tube (Annas, 1984, 1985).

Nancy Cruzan. Nancy Cruzan was a 25 year old woman in a persistent vegetative state as a result of a 1983 automobile accident in Missouri. Her family consented to insertion of a gastrostomy tube hoping that improved nutrition would help their daughter to regain consciousness. Unfortunately, this did not help her condition. She was cared for as a non-responding patient, and did not improve over five years. After consulting with ethicists, lawyers, and nurses who assured them that it would not be illegal or unethical to remove her feeding tube, her family requested that the tube be removed. The physicians refused to remove the life support unless the move was directed by a Court order (O'Rourke, 1991).

The Missouri Court granted permission for the feeding and hydration administered through the gastrostomy tube to be discontinued. The State Attorney General appealed the decision to the Missouri Supreme Court. The Missouri Supreme Court reversed the decision by a narrow margin because there was not "clear and convincing" evidence that Nancy would herself choose to have life support removed. The "clear and convincing" evidence should be directed toward the best interest of the patient, not to the decision he or she would make in these circumstances (O'Rourke, 1991). The U.S. Supreme Court affirmed the state's right to require "clear and convincing" evidence; in addition, it indicated that the administration of artificial food and fluids is a medical treatment and affirmed the

right of competent people to make decisions for themselves regarding such treatment. Lastly, the justices implied that people in a persistent vegetative state are in terminal illness, justifying the withdrawal of food and fluids when indicated. Following the United States Supreme Court decision, some of Ms. Cruzan's friends came forward to testify that Nancy had indicated that she did not want to be sustained by artificial means, and the Court allowed the feeding tube to be removed (O'Rourke, 1991). She died shortly thereafter.

Karen Ann Quinlin. The parents of Karen Ann Quinlan, a 21 year old patient in a persistent vegetative state, asked to be designated as her guardians and, after she suffered two periods of anoxia, requested that her ventilator be removed. The New Jersey Supreme Court, in a unanimous decision, allowed the removal, on the basis of Karen's constitutional right of privacy, which the Court said would be lost unless her parents were given authority to exercise it on her behalf. This case began the national discussion concerning decision making for incompetent patients (Annas, 1990).

After the ventilator was removed, Karen Quinlin continued to breathe. When asked if he would seek legal permission to remove her food and fluids, her father said such a move would be unacceptable. Karen Quinlin lived for ten years following the removal of her ventilator.

Claire Conroy. Claire Conroy was a single, 84 year old woman who lived in a nursing home in New Jersey. She suffered from severe organic brain syndrome, chronic decubitus ulcers, urinary tract infection, heart disease, hypertension, and diabetes. She was unaware of her surroundings, had primitive brain functioning, no cognitive ability, and there was no expectation that her condition would improve. Her only surviving relative was her nephew, who was appointed her guardian, and who had placed her in the nursing home. In 1982, Ms. Conroy was admitted to a hospital for treatment of her gangrenous leg. Upon admission, a nasogastric tube was inserted for feeding purposes. Amputation was recommended to prevent death; however, the nephew refused. Rather, he asked that the feeding tube be removed; the physician refused. When Ms. Conroy was transferred back to the nursing home, removal of the tube was again refused, so her nephew filed suit (Annas, 1985).

The Trial Court authorized the removal of the feeding tube; this decision was stayed pending appeal. Mrs. Conroy died shortly after the original decision, with the feeding tube in place (Annas, 1983). Following her death, the Appellate Division reversed the Trial Court's decision stating that removal of a feeding tube would be homicide, since Mrs. Conroy would not have died of an existing medical condition, but from dehydration and starvation. The case then went to the New Jersey Supreme Court. The Court rejected any legal distinction between actively hastening death by terminating treatment and passively allowing a person to die, between withholding and withdrawing life-sustaining treatment, and between ordinary and

extraordinary treatment. They stated that competent patients have the right to refuse any treatment, and have the right to demand that any ongoing treatment be discontinued (Annas, 1985).

Clarence Herbert. In California, Clarence Herbert, a 55 year old race track guard, suffered a cardiac arrest while in the recovery room after surgery, was revived, and placed on a mechanical ventilator. Within three days he was determined to be in a deeply comatose state and not likely to recover. When informed of his condition, his family requested that all life-sustaining equipment be removed. The ventilator was removed, and he continued to breathe. Two days after his intravenous tubes were removed, Mr. Herbert died (Annas, 1985; Lo, 1984).

Mr. Herbert's two physicians, Robert Nejdl and Neil Barber, were charged with murder for terminating the feeding. The Court concluded that the cessation of life support measures is not an affirmative act, but rather a withdrawal or omission of further treatment. In addition, it concluded that medical procedures to provide nutrition and hydration were more similar to other medical procedures than to typical ways of providing nutrition. The Court investigated the duty of physicians to continue treatment, and found that physicians have no duty to continue treatment that is futile or useless. Since there was evidence that Mr. Herbert's wife ordered termination in a manner consistent with the patient's wishes, the Appeals Court affirmed the original decision dismissing the case (Annas, 1985; Lo, 1984).

Paul Brophy. Paul Brophy, a 48 year old firefighter, suffered a subarachnoid hemorrhage as a result of a ruptured aneurysm. He regained consciousness, and after waiting two weeks for the cranial swelling to subside, he underwent a craniotomy, and never regained consciousness. His wife authorized the placement of a gastrostomy tube. More than a year later, doctors, nurses, and administrators refused to remove the tube, and Mrs. Brophy asked the Massachusetts Court to authorize the withholding of all medical treatments from her husband, including artificial nutrition and hydration (Annas, 1986).

At trial, a great deal of evidence was presented to indicate that, if Mr. Brophy could speak, he would want the artificial nutrition terminated. On the basis of this evidence, the trial judge concluded that if Mr. Brophy were presently competent, his preference would be to forego the food and water, and, thereby, terminate his life. The judge ignored Mrs. Brophy's wishes, and applied his own best interests test. The judge argued that, aside from the injury to his brain, Brophy's general state of health was good, and that focus should be on the quality of treatment furnished, and not on the quality of Brophy's life. In addition, he concluded that denying a patient food and water will inevitably, in each and every instance, guarantee and cause the death of the patient. By arguing in this manner, the judge granted more rights to the feeding tube than to the patient (Annas, 1986).

Dietitians' Attitudes and Beliefs about Feeding the Terminally Ill Patient

Much medical, legal, and bioethical discussion has centered on withholding or withdrawing nourishment from adults who are terminally ill or in persistent vegetative states, yet few have considered the role of the dietitian. In a study by Wall et al. (1991), a questionnaire was sent to half of the registered dietitians who were members of ADA's Nutrition Support Dietetic Practice Group. Subjects were asked to rank nine conceptual variables that might influence their perspective regarding discontinuation of nourishment for four methods of feeding: oral, invasive enteral (surgical insertion, great discomfort, ie., gastrostomy tube), non-invasive enteral (no surgical insertion, some discomfort, ie., nasogastric tube) , and total parenteral nutrition (TPN). A seven-point Likert scale was used to assess response intensity (strongly agree to strongly disagree). Variables which were considered include: nearness of death, personal requests to discontinue feeding, patient's age, whether feeding caused pain, and whether feeding became too costly. The last variable on each question was "never", to indicate that under no circumstances would discontinuing nourishment be acceptable. Dietitians were asked about their role in decisions about patient feeding and nonfeeding and about who they thought should participate in such decisions. They were also asked about general work experience and about their experience working with terminally ill or comatose patients. A two-way multivariate analysis of variance (MANOVA), was used to determine significant differences among the four feeding methods.

Respondents had an average of 9.9 years of work experience in the field of dietetics. More than 93% of dietitians believed that the physician, patient, and family should be involved in decisions about feeding and nonfeeding; 84% believed that registered dietitians also should be involved in feeding decisions. Dietitians reported that physicians, family members, and patients have the greatest involvement in decisions about feeding where the dietitian does not participate. Among respondents, 59% said they currently participate in feeding and nonfeeding decisions, and 32% said they did not (Wall et al., 1991).

Dietitians indicated that their decision to continue or discontinue nourishment would be affected by the method of feeding being used. Responses regarding use of TPN were significantly different from responses regarding the other three feeding methods. Where death is imminent, dietitians would more likely agree with discontinuing TPN than the other methods under the same conditions. The average agreement for discontinuing oral feeding was significantly different from discontinuing TPN feedings and invasive enteral feedings, suggesting that dietitians were less likely to stop oral feeding even in the face of imminent death. Where death was likely but not imminent, dietitians disagreed with discontinuing feeding overall (Wall et al., 1991).

Dietitians were more likely to stop feeding because of a patient's request than because of a guardian's request, regardless of feeding method. Dietitians strongly disagreed with discontinuing nourishment based solely on patient age. For all

feeding methods, dietitians agreed most that if feeding causes pain, death is imminent, or it is the patient's request, the method of feeding should be stopped (Wall et al., 1991).

In considering a patient's nutrition care, it is important that each case be handled on an individual basis. Dietitians may want to keep in mind that the patient's right to self-determination is most important and that a patient's decision to forego nutrition does not mean professional failure (Wall et al., 1991).

In a study by Luby et al. (1991), 100% of the dietitians surveyed felt that their primary responsibility in patient care was to the patient and the protection of the quality of life. Of dietitians surveyed, 82% considered food and fluid basic and felt that all patients should receive it as part of "human care"; 69% felt that food and fluids, that sustain life, should not be withheld or removed unless shown to be clearly useless.

The researchers concluded that dietitians need to understand moral responsibility for patients, and learn to put the patient's wishes ahead of their own beliefs. Decisions should be well reasoned, not intuitive and emotional. Higher education seems to correlate with an individual's moral reasoning, and ethics education influences the development of sound moral judgment. Ethics education should be expanded to assist future practitioners to give the best possible care to their patients (Luby et al., 1991).

Ethics Education in Supervised Experience Programs in Dietetics

Ethical dilemmas encountered by dietetic practitioners are increasing and may be more difficult to resolve than in the past. This greater frequency is accompanied by a heightened awareness of ethics that may be due to a variety of factors including technological advances in medicine and biology, and significant changes occurring in basic social institutions such as the family (Anderson, 1991). The type of ethics training that dietetic practitioners receive in their dietetics education program will determine how prepared and qualified they will be to deal responsibly and effectively with these issues.

A study by Edelstein (1992), compared the development of moral judgment in dietetics students before and after their dietetics training programs. The researcher hypothesized that greater moral development would occur in supervised practices that allow students more experiences promoting moral growth, such as clinical rotations with patients, peer discussions on ethical issues, and access to instructors trained in ethics. Edelstein used a mailed questionnaire based on Rest's Defining Issues Test, (Rest, 1979), a proven measure of moral judgment.

The results from this study indicated that, in general, programs that fostered peer discussion of moral dilemmas facilitated moral growth more than programs that did not emphasize this aspect. When asked to describe their ethics instructor's qualifications, 11 of the 18 program directors combined services of a regular faculty member or a dietitian and a trained ethicist, philosopher, or other person brought

in especially to teach ethics. In general, the hypothesis that programs that provided more opportunities for interaction and practice would promote greater moral growth was confirmed (Edelstein, 1992).

As professionals, dietetic practitioners require training in how to meet the ethical challenges that will continue to exist. In a study by Anderson (1991), directors of dietetic training programs were asked to complete a questionnaire about the formal ethics instruction provided in their program. Of the respondents, 67% reported that formal instruction in ethics was available for their students. Ethics was taught as a part of another course, rather than as a separate course concerning ethical issues in dietetics, in 72.2% of the programs. Of the faculty teaching ethics who were dietitians, 34.8% classified their specialty as clinical, 11.9% as community, and 24% as management; 29.3% of the ethics faculty was classified as "other", including educators, generalists, program directors, bioethicists, medical law consultants, physicians, social service personnel, and human resource training managers. When asked to list all courses in which ethics was taught, the most frequently identified course titles were clinical dietetics/nutrition, orientation/instruction to dietetics, food service management, dietetic seminar, and professional seminars. Directors reported that the most critical ethical issues for students to address are feeding issues, confidentiality, honesty, integrity, patients' rights, right to die, and ethical business practices. The majority of directors expressed concern and support for the teaching of ethics in dietetic training

programs.

According to Edelstein's Ethics Curriculum Guide (1992), students should have a 12-week classroom experience and continual patient care experience. The curriculum should strive to meet the following four goals:

1. Students will become familiar with appropriate conduct as delineated by the Standards of Professional Responsibility (American Dietetic Association, 1983).
2. Students will become familiar with the medical terminology used in professional journals regarding the ethical dimensions of nutrition care (Schiller, 1988).
3. Students will be able to identify the ethical and legal dimensions of the nutrition care of patients (Brody, 1975; Dresser, 1985).
4. Students will increase their sensitivity to the ethical issues of patient care.

This curriculum is helpful in that it describes the goals of moral development which each student should achieve.

The American Dietetic Association Ethics Committee encourages educators to use the Code of Ethics in curriculum planning to help students understand personal and professional ethics. Exposure to legal decisions in health care will help students become aware of the diverse opinions regarding life-sustaining procedures. Familiarization of their state's legal position on such issues can help raise the

students' consciousness concerning legal responsibility. Role playing, or case enactments, with opportunities to make shared decisions may stimulate critical thinking skills (Luby et al., 1991). In addition, continuing education on ethical issues, as well as lectures given by experts in biomedical ethics, will help the dietetic professional develop and practice moral reasoning skills.

Summary

Ethical issues pervade each aspect of our professional and personal lives. The cases presented demonstrate that the word "ethical" has a great number of interpretations and the definition of this word is often decided by the courts in our legal system. As seen in the cases presented, all professionals may not have the same value system. To be ethical, the most morally desirable action must be determined when one is faced with conflicting value systems (Neville and Chernoff, 1988). Some dietitians may reason with respect to absolute principles of right and wrong, while others may be more contextually influenced with regard to the particular situation in ethical decision-making. It is crucial for the dietitian to be qualified to make ethical decisions when faced with moral dilemmas in the workplace. The skills needed to make these difficult decisions are developed in the dietetics training program and through continued education. Dietetics education in academic and supervised experience programs must include quality ethics instruction in order to prepare dietitians for the ethical dilemmas they will face in the future.

Chapter 4

Methodology

Subjects

Subjects were 144 dietitians living in Virginia in January, 1993 who were members of the Virginia Dietetic Association with one to three years of clinical experience. The subjects' names and addresses were obtained by selecting eligible subjects from the responses to similar research conducted by Dr. L. J. Taper who surveyed all active members of the Virginia Dietetic Association (1993). Study results represent those 104 participants (a 72.2% response rate) who responded to the survey instrument.

Instrumentation

The study instrument was a mailed questionnaire (Appendix B). Approval to conduct the study was obtained from Virginia Tech's Institutional Review Board for Studies involving Human Subjects (Appendix C). This instrument was most appropriate because the sample was geographically spread out throughout Virginia. 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.

Part I of the questionnaire included ten questions designed to assess the attitudes and beliefs of the subjects regarding ethical dilemmas in feeding the

terminally ill patient. These questions were adapted from Edelstein's Ethics Curriculum Guide (Edelstein, 1992), and Luby's comparison of attitude responses between Registered Dietitians (RD) and Registered Nurses (RN), (Luby et al., 1991). Part II was comprised of twelve questions which determined whether ethics is being taught, the characteristics and qualifications of faculty members who teach ethics, course titles and departments in which ethics courses are taught, types of instructional methods used to teach ethics, and ethical issues covered in dietetics supervised experience programs. It also determined which resources subjects use in their decision-making process when faced with ethical dilemmas. These questions were adapted from Anderson's survey of dietetics educators regarding dietetic practitioners' formal ethics instruction in academic and practice programs (Anderson, 1991). In addition, subjects were asked whether or not they feel that their ethics training was adequate. If respondents had not had any degree of formal ethics training (question 2), they were instructed to skip questions 3-9 and resume at question 10 (Part II). Only respondents with some degree of formal ethics training responded to the above questions about ethics training. Part III consisted of four multiple-choice questions pertaining to demographic data, including age, gender, and level of education.

Part II and Part III of the questionnaire were coded as nominal level values for computer analysis. In Part II, it is important to note that low scores on each question indicated positive responses (ie., yes, great, very much) and high scores

indicated negative responses (ie., no, little, none). Responses ranged from very much to none, with 1 equal to very much and 4 equal to none. Part I was scored using four Likert-type response choices ranging from "strongly agree" to "strongly disagree" (1-4).

The instrument was pretested, approximately two weeks prior to the scheduled mailing, with faculty and graduate students in the Department of Human Nutrition and Foods, the Department of Sociology, the Department of Statistics and the Department of Religion at Virginia Tech. These individuals were asked to evaluate the questionnaire in terms of whether they believed it would accomplish the study objectives. After pretesting, the researcher assembled comments from these individuals in order to improve upon the questionnaire design. This pretest allowed the researcher to answer the following questions: (1) Is each of the questions measuring what it is intended to measure?, (2) Are all the words understood?, (3) Are questions interpreted similarly by all respondents?, (4) Does each close-ended question have an answer that applies to each respondent?, (5) Does the questionnaire create a positive impression, one that motivates people to answer it?, (6) Are questions answered appropriately? (Are some missed, and do some elicit uninterpretable answers?), (7) Does any aspect of the questionnaire suggest bias on the part of the researcher? (Dillman, 1978).

The questionnaire mailing included a letter of invitation to the subjects to describe, and to invite subjects to participate in, the study (Appendix D). This letter

informed the subjects that the study was a follow-up to a similar study conducted by Dr. L. J. Taper, and explained that its focus was on overall ethics training related to dietetics. A follow-up postcard was mailed one week following the questionnaire mailing to serve as a reminder, and to express gratitude for subjects' participation (Appendix E). Second and third follow-up letters were not mailed due to a clerical error and high response rates to the initial mailings.

Data Analyses

Data were coded as nominal and ordinal level values for computer analysis using the Statistical Analysis System (SAS Institute Incorporated, SAS Circle, Box 8000, Cary, N.C. 27512-8000). Frequencies were obtained for possible responses to each question. The analysis of Part I and Part II included a correlation analysis using Pearson's Correlation Coefficient (Pearson's r) followed by Analysis of Variance (ANOVA) between selected variables (Jaegar, 1983). The level of significance was set at $p < .05$, prior to interpreting the results.

Chapter 5

Results

Response Rate

Active members of the Virginia Dietetic Association (VDA) living in Virginia as of January, 1993 with one to three years of clinical experience made up the sample for this study. Of the 147 individuals to whom questionnaires were originally mailed, two had moved out of the state, and their questionnaires were returned by the post office. No attempt was made to redeliver these questionnaires since the individuals were no longer eligible to participate. In addition, one questionnaire was returned because the address was not sufficient and, since the investigator was unable to obtain the correct address, this questionnaire was not deliverable. Of the 144 questionnaires which were successfully delivered, 104 were returned completed, giving a response rate of 72.2 percent. All questionnaires received were included in the tabulation of results.

This high response rate is possibly due to the fact that the study was a follow-up to similar research in which the individuals had already participated which elicited dietitians' opinions about the termination of nutritional support in terminally ill elderly patients. The present study focused on attitudes about nutritional support for terminally ill patients in general and, further, determined overall ethics training in dietetics education. The "follow-up" aspect of the research may have motivated the respondents since it showed that research in this area is ongoing. In addition,

the individuals surveyed were a highly motivated group of professionals who probably shared a great deal of interest in the ethical concerns presented in the questionnaire.

Description of Respondents

The demographic questions (Part III, questions 1-4) were developed to determine personal variables about respondents such as their age, gender, level of education, and the type of supervised experience program in which they might have participated. Responses were analyzed using frequency distribution; results are indicated in Table 1. Of the 104 respondents, 101 were female (97%) and 3 were male. The VDA sample chosen was representative of the American Dietetic Association (ADA) in terms of gender, since 97% of ADA members are female (Wall et al., 1991). Most of the respondents were under 40 (64 individuals (61.6%) and held a bachelor's degree (48 individuals (46.2%) or a master's degree (50 individuals (48.1%). Almost half of the respondents completed a dietetic internship (44 individuals (42.7%) and 25 (24.3%) indicated another type of experience program which was termed "other". One individual did not answer this question. Individuals in the "other" category completed a qualifying work experience with a bachelor's degree (2), a qualifying work experience with a graduate degree (19), a traineeship (2), and a master's degree with teaching and research (1); one indicated that she had not completed a supervised experience program.

Table 1: Demographic Characteristics of Respondents.

Characteristic	Frequency	Percent	Freq. Missing
1. Age:			
20-29	29	27.9	0
30-39	35	33.7	
40-49	22	21.2	
50 and older	18	17.3	
2. Supervised Experience Program Completed:			
AP4	8	7.8	1
CPD	26	25.2	
Dietetic Internship	44	42.7	
Other	25	24.3	
3. Gender:			
Male	3	2.9	0
Female	101	97.1	
4. Highest level of education:			
Bachelor's degree	48	46.2	0
Master's degree	50	48.1	
Doctorate	6	5.8	

Dietitians' Attitudes Regarding Ethical Issues

Part I of the questionnaire provided an opportunity for the respondents to share their attitudes with respect to specific ethical issues. Respondents were instructed to share only their personal beliefs regardless of external guidelines such as, legal requirements, professional guidelines, or institutional policies. Frequencies and percentages were obtained for each scaled response in Part I of the questionnaire (questions 1-10) and are shown in Table 2. It is important to note that the scale used ranged from 1-4, with 1 equal to agree and 4 equal to disagree. More respondents disagreed or disagreed somewhat that a terminally ill patient in their care should always be provided with nutritional support. The majority (53 (51%) agreed and 21 (20.2%) agreed somewhat) of respondents believed they would feel comfortable honoring a terminally ill patient's wish to discontinue nutritional support. Most (87 individuals (84%) either agreed or agreed somewhat that it is ultimately the patient's decision whether to continue nutritional support. Similarly, close to 90% (93 individuals) agreed or agreed somewhat that the family of the patient has the right to make decisions regarding nutritional support, consistent with the patient's wishes. Attitudes expressed in questions 5 and 6 were, in contrast, more widespread. When asked if there is an ethical duty on the part of the dietitian to continue nutritional support for a terminal patient, the number of respondents who agreed or disagreed was almost equal. Forty percent (41 individuals) agreed to some extent that nutrition should never be withheld because to do so would end life. In

Table 2: Responses to Questionnaire Part I: Ethical Issues.

	Question	Agree	Agree Somewhat	Disagree Somewhat	Disagree	Freq. Missing
1.	In my opinion, a terminally ill patient should always be provided with nutritional support.	28 26.9%	22 21.2%	34 32.7%	20 19.2%	0
2.	If a terminally ill patient were in my care, I would feel comfortable honoring his or her wish to stop nutritional support.	53 51.0%	21 20.2%	22 21.2%	8 7.7%	0
3.	It is ultimately a terminally ill patient's decision whether nutritional support should be continued.	61 58.7%	26 25.0%	10 9.6%	7 6.7%	0
4.	A comatose patient's family has the right to make a decision, consistent with the patient's wishes, about discontinuing nutritional support for the patient.	71 68.3%	22 21.2%	8 7.7%	3 2.9%	0
5.	If a patient is truly terminal, there is an ethical duty on the part of the dietitian to continue nutritional support for that patient.	29 27.9%	21 20.2%	33 31.7%	21 20.2%	0
6.	Something as basic as nutrition should never be withheld because to do so would end life.	19 18.4%	22 21.4%	36 35.0%	26 25.2%	1
7.	I consider nutritional support for the terminally ill patient a medical treatment which can be stopped like a respirator or any other life-support mechanism.	42 40.8%	30 29.1%	15 14.6%	16 15.5%	1
8.	I could make a decision to discontinue nutritional support for a loved one, if I felt it was consistent with his or her wishes.	48 46.6%	29 28.2%	14 13.6%	12 11.7%	1
9.	It is a terminally ill patient's right to discontinue all nourishment.	68 66.0%	22 21.4%	7 6.8%	6 5.8%	1
10.	My feelings regarding the above issues would be the same for a young adult as they would be for an older adult.	59 57.3%	28 27.2%	13 12.6%	3 2.9%	1

contrast, the majority of respondents (72 individuals (70%)) agreed or agreed somewhat, that nutritional support is a medical treatment which can be stopped like any other life-support mechanism. When asked if they could make a decision to discontinue nutritional support for a loved one, if it was consistent with the loved one's wishes most agreed to some degree. The majority (87.4%) of respondents agreed that it is the patient's right to discontinue all nourishment. Since this question was actually question 3 reworded, it not surprising that the responses were almost identical. Finally, the majority of the respondents (84.5%) believed that their feelings about the ethical issues would be the same for a young adult as for an older adult.

To determine the overall attitudes of respondents regarding ethical issues, the responses to questions in Part I were summed, and mean attitude scores were determined. A lower mean score indicated the use of absolute principles in decisions regarding termination of nutritional support; a higher score indicated that individuals reasoned contextually and were, perhaps, influenced by the wishes of the terminally ill patient and those of his or her family. Overall, about 36% (37 people) used absolute principles in their reasoning, and the remaining 64% (67 people) reasoned contextually about these issues.

Ethics Training Related to Dietetics

Dietitians were asked in Part II of the questionnaire about the ethics training

they had received in dietetics education in academic or supervised experience programs, at the worksite, or in coursework. The scale used ranged from "very much" to "none", and was coded for analysis with 1 equal to "very much" and 4 equal to "none". Results are indicated in Table 3. The majority of respondents reported some (43 people (42.2%) or little (47 people (46.1%) informal ethics training. More than half of the respondents (57 people (55.3%) reported having no formal ethics training at all. Those who had had no formal ethics training were instructed to skip questions 3-9 and begin responding again at question 10. Respondents with any degree of formal ethics training (46 people or 44.7%) proceeded to complete this part of the questionnaire.

Question 3 asked how extensively different teaching modes were used in ethics training, including case studies, open discussions, exposure to legal decisions regarding ethical dilemmas, role-playing, lectures, and films. Open discussions (32 people (69.6%) answered "very" or "somewhat") and lectures (30 people (63.8%) answered "very" or "somewhat") were the most widely used. Films and role-playing, were seldom used in ethics education.

Question 4 asked how much of the ethics training was taught by the following professionals: dietitian, bioethicist, physician, clergy member, trained ethicist/philosopher, sociologist. The majority of respondents said that a dietitian taught "very much" or "some" of their ethics training (9 people (19.6%) "very much" and 24 people (32.6%) "some"). Ethics was rarely taught by a bioethicist (5 people

Table 3: Responses to Questionnaire Part II - Ethics training related to dietetics.

Question	very much	some	little	none	Freq Missing
1. How much informal ethics training have you had?	7 (6.9%)	43 (42.2%)	47 (46.1%)	5(4.9%)	2
	> 1 course	1 course	some exposure	none at all	Freq Missing
2. How much formal ethics training have you had?	4 (3.9%)	11 (10.7%)	31 (30.1%)	57 (55.3%)	1
3. How extensively was each of the following covered in your ethics training:	very	somewhat	slightly	not at all	Freq Missing
Case Studies	3 (6.4%)	17 (36.2%)	16 (34.0%)	11 (23.4%)	57
Open Discussions	13 (28.3%)	19 (41.3%)	12 (26.1%)	2 (4.3%)	
Exposure to legal decisions regarding ethical dilemmas	8 (17.0%)	12 (25.5%)	15 (31.9%)	12 (25.5%)	
Role-Playing	1 (2.2%)	5 (10.9%)	8 (17.4%)	32 (69.6%)	
Lectures	12 (25.5%)	18 (38.3%)	11 (23.4%)	6 (12.8%)	
Films	1 (2.1%)	7 (14.9%)	11 (23.4%)	28 (59.6%)	
4. How much of your ethics training was taught by each of the following professionals:	very much	some	little	none	Freq Missing
Dietitian	9 (19.6%)	15 (32.6%)	10 (21.7%)	12 (26.1%)	58
Bioethicist	1 (2.2%)	4 (8.9%)	5 (11.1%)	35 (77.8%)	
Physician	4 (8.7%)	8 (17.4%)	3 (6.5%)	31 (67.4%)	
Clergy member	5 (10.9%)	6 (13.0%)	7 (15.2%)	28 (60.9%)	
Trained ethicist/philosopher	6 (13.6%)	8 (18.2%)	4 (9.1%)	26 (59.1%)	
Sociologist	0	14 (30.4%)	3 (6.5%)	29 (63.0%)	
5. How much of your ethics training was taught in each of the following departments:	very much	some	little	none	Freq Missing
Religion/Theology	3 (7.0%)	8 (18.6%)	2 (4.7%)	30 (69.8%)	57
Philosophy	6 (14.0%)	9 (20.9%)	5 (11.6%)	23 (53.5%)	
Nutrition/Food Science	8 (18.2%)	16 (36.4%)	11 (25.0%)	9 (20.5%)	
Sociology	1 (2.3%)	14 (31.8%)	8 (18.2%)	21 (47.7%)	
6. How much were each of the following ethical issues covered in your ethics training:	very much	some	little	none	Freq Missing
Feeding issues	11 (23.4%)	18 (38.3%)	13 (27.7%)	5 (10.6%)	58
Confidentiality	18 (38.3%)	16 (34.0%)	6 (12.8%)	7 (14.9%)	
Honesty/integrity	15 (32.6%)	15 (32.6%)	11 (23.9%)	5 (10.9%)	
Patient's rights	17 (36.2%)	16 (34.0%)	8 (17.0%)	6 (12.8%)	
Right to die	13 (27.7%)	18 (38.3%)	11 (23.4%)	5 (10.6%)	

Table 3 (Contd): Responses to Questionnaire Part II - Ethics training related to dietetics.

7. Of the following courses, which one course incorporated ethics as an important structural component?	Frequency	Percent	Freq Missing
Clinical Dietetics/Nutrition	10	24.4	63
Orientation/Introduction to Dietetics	1	2.4	
Dietetics or Professional Seminar	12	29.3	
Bioethics	4	9.8	
Sociology	5	12.2	
Religion	0	0	
Philosophy	9	22.0	
8. The following case laws were reviewed in my ethics training:	**Yes**	**No**	**Freq Missing**
Karen Quinlin	24 (57.1%)	18 (42.9%)	62
Elizabeth Bouvia	4 (10.8%)	33 (89.2%)	67
Nancy Cruzan	15 (35.7%)	27 (64.3%)	62
Paul Brophy	2 (5.3%)	36 (94.7%)	66
Claire Conroy	3 (7.9%)	35 (92.1%)	66
Clarence Herbert	3 (8.1%)	34 (91.9%)	67
9. How would you rate your ethics training?	**Frequency**	**Percent**	**Freq Missing**
Excellent	1	2.1	57
Good	8	17.0	
Fair	21	44.7	
Poor	17	36.2	
Non-Existent	0	0	
10. How confident do you feel that your ethics training has prepared you for the ethical dilemmas you may face on-the-job in the future?	**Frequency**	**Percent**	**Freq Missing**
Very	4	4.1	6
Somewhat	36	36.7	
Slightly	32	32.7	
Not at all	26	26.5	
11. To what extent do you bring your spiritual beliefs to bear in your ethical decision-making?	**Frequency**	**Percent**	**Freq Missing**
Great	32	31.1	1
Some	35	34.0	
Little	22	21.4	
Not at all	14	13.6	
12. I base my decisions about ethical dilemmas mainly on:	**Frequency**	**Percent**	**Freq Missing**
Formal training	5	5.0	4
Informal training	18	18.0	
Spiritual beliefs	32	32.0	
Family values	24	24.0	
Personal experience	21	21.0	

(11.1%) answered "very much" or "some").

In question five, respondents were asked how much of their ethics training was taught in each of the following departments: religion/theology, philosophy, nutrition/food science, and sociology. Over half (55%) 4 people) of the respondents said that ethics training was taught in nutrition/food science "very much" or "some".

Question 6 asked respondents how much the following ethical issues were covered in their ethics training: feeding issues, confidentiality, honesty/integrity, patients' rights, and right to die. Not surprisingly, the majority of respondents said that all of the issues were covered "very much", or "some", in their ethics training. The most popular issue covered was confidentiality (18 people (38.3%) answered "very much" and 34 people (34%) answered "some").

Respondents were asked (question 7) to choose the one course, which best incorporated ethics as an important structural component, from the following: dietetics/nutrition/food science, bioethics, sociology, and philosophy. Fifty-six percent (23 people) chose dietetics/nutrition/food science. When asked which case studies were reviewed in their ethics training (question 8), the case of Karen Quinlin was studied the most (24 people (57.1%), followed by that of Nancy Cruzan (15 people (35.7%). Very few respondents had reviewed the case studies of Elizabeth Bouvia, Paul Brophy, Claire Conroy or Clarence Herbert.

When asked to rate their ethics training (question 9), only 1 person gave an "excellent" rating; 8 (17%) rated their training as "good". The other 80.9% (38

people) of respondents rated their training as "fair" or "poor". All respondents were instructed to respond to question ten. Question 10 asked respondents to rate their confidence level, earned through ethics training (formal or informal), in dealing with ethical dilemmas at the worksite. Forty-one percent (40 people) of the respondents felt "very", or "somewhat", confident to face ethical dilemmas, while 59% (58 people) felt only "slightly", or "not at all", confident.

The last two questions in Part II dealt with the evaluative framework which respondents use to make ethical decisions. Question 11 asked to what extent respondents felt they brought spiritual beliefs to bear in ethical decision-making. Sixty-five percent (67 people) said they brought spiritual beliefs to bear to a great extent or to some extent. Fourteen percent (14 people) said that they did not bring spiritual beliefs to bear at all in ethical decision-making. When asked what their decisions about ethical dilemmas are based on (question 12), respondents gave a variety of responses: ethics training (23 people (23%), spiritual beliefs (32 people (32%), family values (24 people (24%), and personal experience (21 people (21%).

To determine the overall level of ethics training of respondents, responses to the questions in Part II were summed, a mean training scores were determined. The 47 respondents who had had some type of formal ethics training and completed this section of the survey, had a mean training level of 2.76 which is between "some" and "little" training and somewhat closer to "little" training. A lower mean training score indicated a great deal of ethics training while a higher mean indicated little or no

ethics training.

Factors Which Influenced Dietitians' Mean Attitude Scores

Analysis of variance (ANOVA) procedures allow the researcher to state or imply the inequality of at least two means by testing the null hypothesis that the means are equal. This procedure (SAS Institute Incorporated, SAS Circle, Box 8000, Cary, N.C. 27512-8000) was used to determine whether attitude scores were significantly affected by selected variables. Results of the Analysis of Variance procedure are shown in Table 4. Respondents, who said they felt very confident their ethics training had prepared them for the ethical dilemmas they may face on-the-job (Part II, question 10) had a significantly higher mean attitude score (3.86, $p<.0258$), than those who answered "somewhat", "slightly", or "not at all" confident (3.17, 2.89 and 2.80, respectively), although it is important to note that there were only 4 respondents in the "very" confident category,. In addition, respondents who felt "very" confident had a lower (indicating that they agreed with the statement) mean response (1.00, $p<.0119$) than those who felt "slightly" confident (1.88, indicating that they "somewhat" agreed) when asked if they would feel the same about the ethical issues with respect to a young adult as they would for an older adult (Part I, question 10). Again, there were only 4 respondents who felt "very" confident which may have skewed the results.

Respondents who said they brought their spiritual beliefs to bear to a great

Table 4: Results of Analysis of Variance procedure for factors which influenced mean attitude scores.

Dependent variable	Independent variable	Degrees of Freedom	Sum of Squares	Mean Square	F Value	Prob
Mean Attitude Score	Level of Confidence (Part II, #10)	3	5.60	1.87	3.23	0.0258
	Extent to which spiritual beliefs brought to bear (Part II, #11)	3	7.93	2.64	4.92	0.0032
	Age	3	6.92	2.31	4.17	0.0079
Would you feel the same about these issues for a young adult as for an older adult? (Part I, #10)	Level of Confidence (Part II, #10)	3	7.15	2.38	3.85	0.0119

extent in ethical decision-making (Part II, question 11) had a significantly lower mean attitude score (2.65, $p<.0032$) than those who answered "little" or "not at all" (3.21 and 3.46, respectively). A significantly higher mean attitude score (3.39, $p<.0079$) was noted in respondents who were 20-29 years old (Part III, question 1) compared to the mean of those who were in the 40-49 years and 50 years and older categories (2.87 and 2.65, respectively).

Using Pearson's Correlation Coefficient, a significant positive correlation was noted between the degree to which respondents said they brought spiritual beliefs to bear in ethical decision-making (Part II, question 11) and mean attitude scores ($r=.35$, $p<.0003$). There was a negative correlation between confidence level (Part II, question 10) and mean attitude scores ($r=-.24$, $p<.0188$). A significant negative correlation was noted between those who said they based their decisions about ethical dilemmas on spiritual beliefs (question 12) and mean attitude scores ($r=-.26$, $p<.0087$). Although the values mentioned above are statistically significant, it is difficult to say what Pearson's r values of this magnitude mean in practical terms. There was not a significant relationship between the type of supervised experience program completed (Part III, question 2) or the level of education (Part III, question 4) and mean attitude scores. These results are shown in Table 5.

Table 5: Significant Pearson Correlation Coefficients between mean attitude scores and factors which influenced mean attitude scores.*

	Correlation Coefficients
Degree to which spiritual beliefs were brought to bear (Part II, #11)	.35
Level of Confidence (Part II, #10)	-.24
Decisions based on spiritual beliefs (Part II, #12)	-.26

*Correlational Analysis (SAS Institute Inc., Cary, NC), $P<.05$

Factors Which Influenced Dietitians' Mean Training Scores

Part II of the questionnaire was analyzed by ANOVA and Pearson's Correlation Coefficient to determine variances and relationships between mean training scores and selected variables. Results of the Analysis of Variance procedure are shown in Table 6. Respondents who were 50 years and older had a significantly lower training score (1.82, $p<.0033$) than those in all other age groups. It is necessary to comment that only 3 respondents comprised this mean which may have affected the results.

Of the respondents who had some level of formal ethics training, those who had reviewed the Karen Quinlin case (question 8) had a significantly lower (2.62, $p<.0102$) training score than those who had not reviewed the case (3.01). Likewise, those who had reviewed the Nancy Cruzan case (question 8) had a significantly lower (2.51, $p<.0054$) training score than those who had not reviewed it (2.93)

Using Pearson's Correlation Coefficients, significant positive correlations were found between mean training scores and the amount of formal ($r=.39$, $p<.0072$) and informal ethics training ($r=.30$, $p<.0425$) the respondents had (question 1 and 2). Significant positive correlations were also noted between mean training scores and (Part II) question 3 through question 7 ($p<.05$). There was also a positive correlation between mean training scores and how respondents rated their ethics training (question 9) with $r=.50$ ($p<.0003$). Again, there was not a significant relationship between the type of supervised experience program completed by

Table 6: Results of Analysis of Variance procedure for factors which influenced mean training scores.

Dependent variable	Independent variable	Degrees of Freedom	Sum of Squares	Mean Square	F Value	Prob
Mean Training Score	Age	3	3.14	1.05	5.32	0.0033
	Karen Quinlin case study reviewed (Part II, #8)	1	1.52	1.52	7.27	0.0102
	Nancy Cruzan case study reviewed (Part II, #8)	1	1.75	1.75	8.64	0.0054

respondents (Part III, question 2) or their highest level of education attained (Part III, question 4) and their mean training scores. The Pearson Correlation Coefficients for the relationships between mean training scores and the above variables are shown in Table 7.

Table 7: Significant Pearson Correlation Coefficients between mean training scores and factors which influenced mean training scores.*

	Correlation Coefficients
Amount of formal ethics training (Part II, #2)	.39
Amount of informal ethics training (Part II, #1)	.30
Part II, Statement:	
3	.53
4	.52
5	.48
6	.53
7	.39
Rating of ethics training	.50

*Correlational Analysis (SAS Institute Inc., Cary, NC), $P<.05$

Chapter 6

Discussion

This study was designed to determine the attitudes and beliefs of dietitians in Virginia, with one to three years of experience, regarding nutritional care for terminally ill patients. In addition, an effort was made to define the format and content of ethics training received in academic and supervised experience programs in dietetics education, as well as the adequacy of the ethics training. This information will help to define the educational needs of future students and indicate specific areas requiring improvement.

This discussion will focus on the evaluative frameworks used in ethical decision-making, as expressed in dietitians' attitudes, and on dietitians' ethics education. It is meant to provide a clearer understanding of the results presented and possible reasons for these results.

Evaluative Frameworks for Dietitians' Attitudes

Part I of the study allowed respondents to share their attitudes about nutritional support for terminally ill patients. Factors which influenced dietitians' mean attitude scores included: age, use of a spiritual basis for ethical decision-making, and confidence level in making ethical decisions. The overall mean attitude score (3.01) indicated that most dietitians reason contextually with regard to each individual ethical dilemma and that their decisions may be influenced by the wishes

of the patient and the patient's family. This majority response may possibly be explained by the fact that over half of the respondents were under 40 years old (61.6%); results are similar to those of a study by Wall et al. (1991), in which 74% of the respondents were under 40 years of age. In this study (Wall et al., 1991), the researchers found that more than 93% of dietitians believed that the patient and family should be involved in decisions about feeding and nonfeeding.

There was a negative correlation between respondents' confidence level and mean attitude scores. Respondents who were more confident with making ethical decisions on-the-job had significantly higher mean attitude scores, meaning they were more contextual in their ethical decision-making regarding nutritional support. This contextual evaluative framework may be used because the "very" confident dietitians understand moral responsibility and are skilled in assisting with complex ethical issues. The decisions they make appear to be well-reasoned, based on logic and arrived at with considerable thought and reflection (Luby et al., 1991). When asked if they would make the same nutritional care decisions for a young adult as they would for an older adult, the "very" confident respondents had a lower mean response than the less confident respondents, indicating that they agreed that they would make the same ethical decisions for young and older adults. Unfortunately, there were only four respondents who felt "very" confident in making ethical decisions which may have disallowed reliable statistical results.

There was a positive correlation between the degree to which respondents

brought their spiritual beliefs to bear in ethical decision-making (question 11) and mean attitude scores. In other words, dietitians who brought spiritual beliefs to bear to a great extent had significantly lower mean attitude scores, indicating the use of absolute principles in ethical decision-making. In contrast, there was a negative correlation between respondents who said they based their ethical decisions on spiritual beliefs (question 12) and mean attitude scores, meaning that dietitians who based their ethical decisions on spiritual beliefs reasoned contextually about the ethical issues presented. The inconsistency of the aforementioned results may be the result of respondents having difficulty defining "spiritual", since the definition was left up to the respondents. Some may have equated "spiritual" with organized religion, leading them to reason using absolute principles of right or wrong. Still, others may have thought of a definition similar to the intended definition: "spirituality is that which acknowledges that the meaning and purpose of physical phenomena are not self-generated or self-authenticated but, instead, are attributed to, and derived from, religious or spiritual sensibilities that are dependent on a transcendent reality that is called God" (Smith, 1992). Those accepting this latter definition may be more likely to reason in a contextual manner.

These inconsistencies may stem from the respondents' difficulty to pinpoint the basis of their ethical decision-making. Our ability to make right and good decisions is not solely a product of formal ethics training, but is may also be rooted in our development-intellectual, social, and educational experiences (Luby et al.,

1991). In contrast to this study, Edelstein (1992) found that there was no significant relationship between strength of religious belief and level of moral development. This difference in results may be because Edelstein asked very broad questions about ethics, while this study focused on the ethical dilemma surrounding the nutritional support of terminally ill patients. It is possible that when people face death, they may be more likely to turn to religious principles for guidance.

There was not a significant relationship between mean attitude scores and the supervised experience program completed or the level of education attained. The former result does not agree with Edelstein's results (Edelstein, 1992), where the researcher found significantly different student scores on a test of moral judgment depending on the type of supervised experience program completed; the highest scores were those of dietitians who had completed an internship program. This may suggest that the supervised experience programs are comparable, or that ethics training is only one of many factors on which dietitians base their ethical decision-making. The lack of a relationship between attitudes and level of education attained is inconsistent with Luby et al. (1991) who found a correlation between higher education and an individual's moral reasoning. Again, this may suggest that ethics training is not a panacea, and that its role in ethical decision-making is small when compared to other factors involved in moral development.

Dietitians' Ethics Education

Overall, more than half of the dietitians surveyed (55.3%) reported that they had had no formal ethics training. In effect, these respondents were unable to complete questions 3 through 9 in Part II of the questionnaire. This result is consistent with that of Luby et al. (1991) who noted that ethics education in the dietetic curriculum appears limited. Although this fact is discouraging, the remaining 44.7% of respondents who did complete the questionnaire were able to provide some valuable insight about the ethics education that is being taught. Dietitians who were 50 years and older had lower mean training scores than those in other age groups, meaning they had more ethics education than younger respondents. This result is possibly misleading because only 3 respondents (of a possible 18 respondents over 50 years) comprised this group, meaning that only three respondents over 50 years had any degree of training and were able to complete this section of the questionnaire.

Respondents who had more ethics training were more likely to have studied cases of Karen Quinlin and Nancy Cruzan. This is not surprising because these are precedent-setting cases regarding the "right to die" and would probably have been studied in most courses which focused on bioethical issues.

The significant positive correlations between mean training scores and the amount of formal and informal training were expected. Respondents with more formal and informal training would select "very much" ("very much"=1), resulting in

lower mean training scores than those with less training ("little"=3, "none"=4). A significant positive correlation was also found between mean training scores and questions 3-7 in Part II of the survey. In other words, respondents who selected "very much" for specific training methods, had a low mean training score (which indicates more training). This positive correlation indicated to the researcher that the questions in Part II could be summed to determine the level of training completed by respondents.

There was a positive correlation between mean training scores and how respondents rated their ethics training. In other words, those respondents with more training rated their training higher. This may suggest that the dietitians who had some level of training were satisfied with the training they had received.

As was noted with the mean attitude scores, there was not a significant relationship between the mean training scores and the supervised experience program completed by respondents. This is not consistent with Edelstein's (1992) findings, where the researcher noted that internships offered longer and more combinations of educational ethics experience, including longer ward rotations for patient care, more exposure to trained ethics instructors, and more combinations of methods for exposure to peer discussion of ethical issues in nutrition care. This may suggest that the respondents had the same amount of training in each supervised experience program. In addition, there was not a significant relationship between level of education completed and mean training scores. This result may indicate that

the amount of ethics training was equally emphasized at all levels of education and that ethics training is probably not the sole basis for respondents' ethical decision-making.

Chapter 7

Summary and Future Research Recommendations

As life-sustaining technology rapidly increases, issues of professional ethics will remain at the forefront of the health care professions, including dietetics. Because nutritional support to sustain life may be withdrawn or withheld from terminally ill patients, it is important to recognize the potential for ethical conflicts among health care professionals. Ethics education in academic and supervised experience programs in dietetics will provide the dietitian with critical thinking skills invaluable to coping with these ethical dilemmas.

A questionnaire was developed to measure the attitudes of dietitians regarding ethical issues, as well as the ethics education received in overall dietetics education. The instrument was administered to 147 dietitians living in Virginia with one to three years of clinical experience. Of the 147 questionnaires mailed, 104 were returned (a 72.2% response rate), and the results were tabulated. Ninety-seven percent of the dietitians who responded were female. Most (62%) were under 40 years of age. The majority had a bachelor's degree (46.2%) or a master's degree (48.1%). Forty-three percent of respondents completed a dietetic internship, followed by the Coordinated Program in Dietetics (CPD, 25.2%) and other types of experience programs (24.3%).

More than half of the respondents had not had any formal ethics training in

their dietetics education (55.3%). The majority of respondents (64%) had a high mean attitude score indicating the use of a contextual framework in ethical decision-making. Of the 47 respondents who had had some level of formal ethics training, the mean training level was somewhat high indicating some or little ethics training, though the level was somewhat closer to "little" training. Of those who had ethics training, only 19.1% rated their training as "excellent" or "good", and over half (59%) of the dietitians felt "slightly" or "not at all" confident that their training had prepared them for the ethical dilemmas they may face at the worksite.

Many of the dietitians (65%) indicated that they brought spiritual beliefs to bear in ethical decision-making. In contrast to the above results, when asked what evaluative framework they used as a basis for ethical decision-making, only 32% chose spiritual beliefs. This inconsistency may be due to an uncertainty about the definition intended for "spiritual", and the respondents' difficulty in identifying the sole basis for their decision-making.

In general, the dietitians in this survey did not receive adequate ethics training in their dietetics education. Those respondents who did have formal ethics training had little confidence in dealing with ethical dilemmas, and did not give their ethics education high ratings. These findings are discouraging since, dietitians will, undoubtedly, have to make ethical decisions regarding issues like those presented in this study.

This questionnaire attempted to assess the attitudes of dietitians in order to

draw attention to the complex nature of these ethical problems. The information gained from this study about the lack of ethics training should aid educators in the development of an ethics education component for academic and supervised experience programs in dietetics.

Future research in this area may focus on probing educators for their opinions regarding the need for ethics training. With the increase in ethics committees in the health care professions and the dietitian's increased involvement with these committees, ethics training is needed. Researchers like Wall et al. (1991), Luby et al. (1991), Anderson (1991), Edelstein (1992) and Taper (1993) remain at the forefront of this question of ethics education in the field of dietetics. Further study by these individuals, as well as others, must continue if the educational needs of future dietitians are to be fulfilled.

It is suggested that other ethical issues be addressed, such as those of patient confidentiality, honesty and integrity, patients' rights, and the right to die (Edelstein, 1992). Ethics education should begin in the classroom to prepare dietitians for the workplace, and to facilitate the moral growth process.

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APPENDIX A

CODE OF ETHICS:
AMERICAN DIETETIC ASSOCIATION

1. The dietetic practitioner provides professional services with objectivity and with respect of the unique needs and values of individuals.
2. The dietetic practitioner avoids discrimination against other individuals on the basis of race, creed, religion, sex, age and national origin.
3. The dietetic practitioner fulfills professional commitments in good faith.
4. The dietetic practitioner conducts himself/herself with honesty, integrity, and fairness.
5. The dietetic practitioner remains free of conflict of interest while fulfilling the objectives and maintaining the integrity of the dietetic profession.
6. The dietetic practitioner maintains confidentiality of information.
7. The dietetic practitioner practices dietetics based on scientific principles and current information.
8. The dietetic practitioner assumes responsibility and accountability for personal competence in practice.
9. The dietetic practitioner recognizes and exercises professional judgement within the limits of his/her qualifications and seeks counsel or makes referrals as appropriate.
10. The dietetic practitioner provides sufficient information to enable clients to make their own informed decisions.
11. The dietetic practitioner who wishes to inform the public and colleagues of

his/her services does so by using factual information. The dietetic practitioner does not advertise in a false or misleading manner.

12. The dietetic practitioner promotes or endorses products in a manner that is neither false or misleading.
13. The dietetic practitioner permits use of his/her name for the purpose of certifying that dietetic services have been rendered only if he/she has provided or supervised the provision of those services.
14. The dietetic practitioner accurately presents professional qualifications and credentials.
    a. The dietetic practitioner uses "RD" or "registered dietitian" and "DTR" or "dietetic technician registered" only when registration is current and authorized by the Commission on Dietetic Registration.
    b. The dietetic practitioner provides accurate information and complies with all requirements of the Commission on Dietetic Registration program in which he/she is seeking initial or continued credentials from the Commission on Dietetic Registration.
    c. The dietetic practitioner is subject to disciplinary action for aiding another person in violating any Commission on Dietetic Registration requirements or aiding another person in representing himself/herself as an RD or DTR when he/she is not.
15. The dietetic practitioner presents substantiated information and interprets

controversial information without personal bias, recognizing that legitimate differences of opinion exist.

16. The dietetic practitioner makes all reasonable effort to avoid bias in any kind of professional evaluation. The dietetic practitioner provides objective evaluation of candidates for professional association memberships, awards, scholarship, or job advancements.

17. The dietetic practitioner voluntarily withdraws from professional practice under the following circumstances:

    a. The dietetic practitioner has engaged in any substance abuse that could affect his/her practice;

    b. The dietetic practitioner has been adjudged by a court to be mentally incompetent;

    c. The dietetic practitioner has an emotional or mental disability that affects his/her practice in a manner that could harm a client.

18. The dietetic practitioner complies with all applicable laws and regulations concerning the profession. The dietetic practitioner is subject to disciplinary action under the following circumstances:

    a. The dietetic practitioner has been convicted of a crime under the laws of the United States which is a felony or a misdemeanor, an essential element of which is dishonesty and which is related to the practice of the profession.

    b. The dietetic practitioner has been disciplined by a state and at least one of

the grounds for the discipline is the same as or substantially equivalent to these principles.

c. The dietetic practitioner has committed an act of misfeasance or malfeasance which is directly related to the practice of the profession as determined by a court of competent jurisdiction, a licensing board, or an agency of a governmental body.

19. The dietetic practitioner accepts the obligation to protect society and the profession by upholding the Code of Ethics for the Profession of Dietetics and by reporting alleged Violations of the Code through the defined review process of the American Dietetic Association and its credentialing agency, the Commission on Dietetic Registration.

APPENDIX B

QUESTIONNAIRE:
ETHICAL ISSUES IN FEEDING THE TERMINALLY ILL PATIENT

ETHICAL ISSUES IN FEEDING THE TERMINALLY ILL PATIENT

This study is about terminally ill patients and ethical issues. There are no "correct" answers to any question. It will take about 15 minutes to complete this questionnaire.

Part I - Ethical Issues

Please circle the number which best describes your personal beliefs. Your answers do not have to agree with your institution's policies, legal requirements or professional guidelines. We are only interested in your personal beliefs, regardless of external guidelines. Nutritional support refers to artificial feeding by enteral or parenteral means.

		Agree	Agree Somewhat	Disagree Somewhat	Disagree
1.	In my opinion, a terminally ill patient in my care should always be provided with nutritional support.	1	2	3	4
2.	If a terminally ill patient were in my care, I would feel comfortable honoring his or her wish to stop nutritional support.	1	2	3	4
3.	It is ultimately a terminally ill patient's decision whether nutritional support should be continued.	1	2	3	4
4.	A comatose patient's family has the right to make a decision, consistent with the patient's wishes, about discontinuing nutritional support for the patient.	1	2	3	4
5.	If a patient is truly terminal, there is an ethical duty on the part of the dietitian to continue nutritional support for that patient.	1	2	3	4
6.	Something as basic as nutrition should never be withheld because to do so would end life.	1	2	3	4
7.	I consider nutritional support for the terminally ill patient a medical treatment which can be stopped like a respirator or any other life-support mechanism.	1	2	3	4
8.	I could make a decision to discontinue nutritional support for a loved one, if I felt it was consistent with his or her wishes.	1	2	3	4
9.	It is a terminally ill patient's right to discontinue all nourishment.	1	2	3	4
10.	My feelings regarding the above issues would be the same for a young adult as they would for an older adult.	1	2	3	4

Part II - Ethics Training Related to Dietetics

Please provide the following information about the ethics training you have received related to dietetics in a supervised experience program, on-the-job, or in other coursework by circling the **one** answer corresponding to your response.

1. How much informal ethics training have you had (ie. reading for personal interest, on-the-job exposure, exposure at various seminars or meetings, etc.)?

very much some little none

2. How much formal ethics training have you received (ie. college courses, courses in your supervised experience program, etc.)?

more than one course one course (3 credits) some exposure none at all

If none at all, SKIP to question number 10!

3. How extensively was each of the following covered in your ethics training:

Case Studies	very	somewhat	slightly	not at all
Open Discussions	very	somewhat	slightly	not at all
Exposure to legal decisions regarding ethical dilemmas	very	somewhat	slightly	not at all
Role-playing	very	somewhat	slightly	not at all
Lectures	very	somewhat	slightly	not at all
Films	very	somewhat	slightly	not at all

4. How much of your ethics training was taught by each of the following professionals:

Dietitian	very much	some	little	none
Bioethicist	very much	some	little	none
Physician	very much	some	little	none
Clergy member	very much	some	little	none
Trained ethicist/philosopher	very much	some	little	none
Sociologist	very much	some	little	none

5. How much of your ethics training was taught in each of the following departments:

Religion/Theology	very much	some	little	none
Philosophy	very much	some	little	none
Nutrition/Food Science	very much	some	little	none
Sociology	very much	some	little	none

6. How much were each of the following ethical issues covered in your ethics training:

Feeding issues	very much	some	little	none
Confidentiality	very much	some	little	none
Honesty/Integrity	very much	some	little	none
Patient's rights	very much	some	little	none
Right to die	very much	some	little	none

7. Of the following courses, which **one** course incorporated ethics as an important structural component? (Choose the title of the course which most closely matches the title of the course you have taken. The exact title is not important. Choose only **one**!)

Clinical Dietetics/Nutrition

Orientation/Introduction to Dietetics

Dietetics or Professional Seminar

Bioethics

Sociology

Religion

Philosophy

8. The following case laws were reviewed in my ethics training:

Karen Quinlan	yes	no
Elizabeth Bouvia	yes	no
Nancy Cruzan	yes	no
Paul Brophy	yes	no
Claire Conroy	yes	no
Clarence Herbert	yes	no

9. How would you rate your ethics training?

excellent good fair poor non-existent

10. How confident do you feel that your ethics training (formal or informal) has prepared you for the ethical dilemmas you may face on-the-job in the future?

very somewhat slightly not at all

11. To what extent do you bring spiritual beliefs to bear in your ethical decision-making?

great some little not at all

12. I base my decisions about ethical dilemmas mainly on (circle only one):

formal training

informal training

spiritual beliefs

family values

personal experience

Part III - Demographic Data

1. My age is:

   A. 20-29

   B. 30-39

   C. 40-49

   D. 50 or older

2. I completed the following ADA accredited supervised experience program:

   A. Approved Preprofessional Practice Program (AP4)

   B. Coordinated Program in Dietetics (CPD)

   C. Dietetic Internship

   D. Other _____
   (please specify)

3. I am:

   A. Male

   B. Female

4. My highest level of education is:

   A. Bachelor's degree

   B. Master's degree

   C. Doctorate

YOUR HELP WITH THIS STUDY IS GREATLY APPRECIATED!!!!!!

APPENDIX C

APPROVAL FROM INSTITUTIONAL REVIEW BOARD VIRGINIA TECH

Virginia Tech
VIRGINIA POLYTECHNIC INSTITUTE
AND STATE UNIVERSITY

Research Division
306 Burruss Hall
Blacksburg, Virginia 24061-0244
(703) 231-6077 FAX (703) 231-4384

MEMORANDUM

TO: Janette Taper
Kirsten Fletcher
Human Nutrition and Foods

FROM: Janet M. Johnson Janet Johnson
Acting Associate Provost for Research

DATE: January 29, 1993

SUBJECT: IRB EXEMPTION/"Ethical Issues in Feeding the Terminally Ill Patient"
93-018

I have reviewed your request to the IRB for exemption for the above referenced project. I concur that the research fall within the exempt status.

However, on the informed consent form, please add the Research Division as a contact for questions concerning the conduct of the research.

Best wishes.

JMJ/gsw

APPENDIX D

COVER LETTER:
JANUARY 29, 1993

January 29, 1993

Dear Virginia Dietetic Association Member:

The use of life-sustaining technologies raises many ethical questions pertaining to withdrawing or withholding a patient's treatment, especially for terminally ill patients. Nutritional support is now among the life-sustaining technologies which may be withheld or withdrawn from these patients.

This is a follow-up to a similar study conducted by my major professor L. Janette Taper, Ph.D., R.D., where you were asked your opinions about the withdrawal of food and fluids from the terminally ill elderly. In this study, we are interested in your attitudes regarding the terminally ill patient, in addition to your overall ethics training related to dietetics. The information you can provide by answering these questions will help to define the educational needs of future students and professionals, and indicate specific areas requiring improvement.

You have been chosen in a sampling of Virginia Dietetic Association members having one to three years of clinical experience. In order for the results to be accurate and useful, it is important that each questionnaire be completed and returned.

Your answers will be completely confidential. The questionnaire has an identification number for mailing purposes only. This is so we can check your name off the mailing list when you return the completed questionnaire. Your name will never be placed on the questionnaire.

You may receive a summary of the results by writing "copy of results requested" on the back of the return envelope, and printing your name and address below it. Please do not put this information on the questionnaire itself.

Please return the questionnaire as soon as possible! We will be happy to answer any questions you may have. Please write or call. The telephone number is (703) 231-7708 or (703) 231-5549. You may also contact the VA Tech Research Division with any questions or concerns at (703) 231-6077.

Thank you for your assistance.

Sincerely,

Kirsten Fletcher
Graduate Student

L. Janette Taper, Ph.D., R.D.
Professor

APPENDIX E

REMINDER POSTCARD: FEBRUARY 5, 1993

Dear Virginia Dietetic Association Member

Last week we mailed you a questionnaire about ethical issues surrounding nutritional support of terminally ill patients. Information you can provide by answering these questions will help develop educational programs for health care professionals.

If you already completed and mailed your responses, please accept our sincere thanks! If not, please do so today. Because we sampled just a small part of the Virginia Dietetic Association, it is extremely important that everyone responds.

If you did not receive a questionnaire, please call us collect at (703) 231-5549 and we will mail another to you today.

Sincerely,

Kirsten Fletcher
Graduate Student

L. Janette Taper, Ph.D., R.D.
Professor
Human Nutrition and Foods

VITA

Kirsten Fletcher was born in Washington, D.C. on June 9, 1969. She attended Virginia Polytechnic Institute and State University (Virginia Tech) in Blacksburg, VA and received a Bachelor of Science Degree in Human Nutrition and Foods in 1991. In the fall of 1991, she began a career as a graduate student working toward a Master of Science Degree in Nutrition at Virginia Tech. She continued her studies at Virginia Tech and completed requirements for this degree in May, 1993.