THE NUTRITION AND HYDRATION OF OLDER ADULT CANCER PATIENTS IN HOSPICE

by

Donna S. Ferrandino

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APPROVED:

S.J. Ritchey, Chair

Eleanor D. Schlenker

L. Janette Taper

Elizabeth M. Bounds

Doris T. Zallen

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Blacksburg, Virginia

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Donna S. Ferrandino

S.J. Ritchey, Chair
Department of Human Nutrition and Foods

(ABSTRACT)

The use of artificial means of nutrition and hydration for terminally ill patients is a controversial topic, involving medical, legal, social, and ethical issues. Often, the patient who is dying in the hospital and ceases to eat and drink receives tube feeding. In contrast, hospice patients are usually not given tube feeding, and emphasis is placed on palliative treatment.

The purpose of the first project was to describe the dietary intake of twelve older adult cancer patients in home hospice care. The mean daily intakes of energy for males ranged from 657 to 2142 kcal per day, or from 28 to 93% of the recommended intake (RI). For females, the mean daily intakes of energy ranged from 358 to 1852 kcal per day, or from 18 to 97% of the RI. Intakes for protein, carbohydrate, fat, and select vitamins and minerals were also highly variable. It was found that some patients survived for extended periods of time with very low intakes of food and fluids. Also, three patients who died during the study showed gradually declining intakes of food and fluids until death.

In the second project, a structured interview was administered to 14 hospice patients and 18 family members to determine their knowledge, perceptions, attitudes, and wishes concerning tube feeding for seriously and terminally
ill patients. Responses to the questions indicated that in general, patients were less opposed to the use of aggressive means of nutrition support than were family members. Also, three of the patients, and only one family member, indicated that they would want to receive tube feeding if they became unable to eat and drink by themselves. Both patients and family members mentioned circumstances related to patient autonomy and prognosis as reasons why it would be permissible to withhold tube feeding from a patient.

The third project presents five case studies of hospice patients who died without receiving artificial nutrition or hydration. The patients' medical records were examined, and their nurses or family members were interviewed about their symptoms and conditions during the dying process. Results indicated that most of the patients experienced no anxiety or restlessness, no nausea or vomiting, and no additional pulmonary problems as death approached. In four patients, pain was either absent or under control. Although four patients stopped eating three to seven days before death, they did not appear to exhibit hunger or thirst during this time. All five patients were reported to have died peacefully. These case studies appear to support the position that terminal starvation and dehydration do not cause pain or discomfort to patients who die without tube feeding. In fact, such patients may experience relief from troublesome symptoms.
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Part I. CARING FOR THE TERMINALLY ILL PATIENT

Introduction

Approximately 75% of terminally ill patients are over the age of 55, and the most common cause of death in terminal patients is cancer (1). Death due to chronic illness, such as cancer, is rarely rapid. The actual physiological dying process ranges from a few hours to days. It is a continuous process as the body and brain are unable to cope with hypoxia, malnutrition, electrolyte imbalance, tumor burden, and toxins that are not cleared from the body as hepatic and renal failure occur. Emotion, cognition, thinking, behavior, and autonomic function all slowly deteriorate and coma usually occurs before death (2).

Enck (2) describes two "roads" to coma in the dying patient. The most common path involves increasing sedation to coma and death. This process does not seem to be traumatic for patients, and attendants generally recall a peaceful death. However, if symptoms are not controlled, the process of death may be more traumatic, resembling the organic brain syndrome of delirium. The patient may experience restlessness, confusion, agitation, hallucinations, myoclonic jerks, seizures, and finally coma. A preterminal delirium can start as many as nine days before death, symptoms often become increasingly severe, and survivors frequently remember a terrible death.

To avoid having the patient experience an uncomfortable death, authors strongly emphasize the need to control symptoms. While the dying patient experiences physical, mental, emotional, social, and spiritual symptoms, this section will be limited primarily to physical problems and conditions, including those which involve nutrition. The
principles of providing medical and nutritional care to the dying patient, and the philosophy of hospice care, will be discussed.

Chapter 1. Medical Care

Definition of Terminal Illness

The meaning of "terminal illness" is not clearly defined with precise criteria. It is difficult to label a patient as terminal because it is difficult to determine prognosis, and since patients occasionally make a surprise recovery. Many physicians are often reluctant to declare formally that a patient is terminally ill (3).

Bayer et al (3) define terminal illness as one in which, on the basis of the best available diagnostic criteria, and in the light of available therapies, a reasonable estimate can be made prospectively and with a high probability that a person will die within a relatively short time. Gallagher-Alired (4) states that a disease is terminal when it has progressed beyond the point at which care for the purpose of disease remission is of any value. The length of this condition is difficult to determine and is highly variable, lasting only days in some patients to weeks or months, and possibly years, in others.

Reuben et al (5) studied clinical symptoms and length of survival in 1,592 terminal cancer patients using data from the National Hospice Study (NHS), a multicenter study that compared hospice and conventional terminal care. For the NHS, a patient was considered terminal when he had been judged by his physician to have an expected survival of six months or less. The authors emphasize the importance of prognosis to plan optimal terminal care, yet state that
accurate measures of prognosis have not been defined. They investigated whether the assessment of clinical symptoms, in addition to performance status, might improve the ability to predict survival.

Results showed that average survival time for the sample population was 63 days, with a median of 35 days and a range of one day to 366 days. By 180 days after entering the study, more than 95% of the patients had died. The authors looked at 14 symptoms, and found prevalences of greater than 50% for eating problems, weight loss, dry mouth, constipation, shortness of breath, and bone pain. Performance status was measured using the Karnofsky Performance status (KPS) Scale which uses an 11-point rating scale that ranges from normal functioning (100) to dead (0). Only 17.5% of the patients had KPS scores of 50 or higher, and 15.3% had scores of 20 or 10.

The authors concluded that the best single prognostic indicator of survival is functional status. To provide further prognostic information, they concluded that five clinical symptoms were found to have independent prognostic value: shortness of breath, eating problems, dry mouth, trouble swallowing, and weight loss. The authors emphasize that the prominence of the four latter symptoms in their model underscores the importance of nutrition status in determining survival in patients with terminal cancer.

Palliative Care

Most physicians and other health professionals have not been trained in providing terminal care (6,7,8). Terminally ill patients are dying, but many do so slowly over a period of weeks or months (9). When cure is no longer a realistic possibility, the appropriate treatment goal becomes
effective disease palliation (6,10). The most important responsibility of the health professional is to attempt to improve the quality of the patient's remaining time of life, especially by controlling noxious symptoms (4,6,9). In palliative care, symptoms, not diseases, are treated (11).

Effective palliative care implies much more than simple handholding or prescribing medicines for pain. Palliative care should be a dynamic process in which all available modalities, including surgery, radiation therapy, chemotherapy, and supportive care services, are employed in an appropriate, skillful, and unique manner for each patient to retard the progress of disease, to relieve symptoms, and in some cases, to prolong life, while fully recognizing that cure is not possible (10). Effective palliative care recognizes that human beings are a composite of physical, social, psychologic, and spiritual elements, so attention is paid not only to physical symptom control, but also to the psychosocial and spiritual issues associated with terminal illness (10,12,13). Optimal palliative care requires an interdisciplinary team effort. The center of the team is the patient and her family, and other team members should include physicians, nurses, physical therapists, dietitians, clergy, social workers, psychologists or psychiatrists, pharmacists, dentists, and volunteers (6,14,15).

Rhymes (6) provides some general guidelines to the health care provider. The patient's wishes regarding treatment should be discussed early, and also as the disease progresses or clinical status changes. Early discussions usually focus on chemotherapy and/or radiation therapy, and the patient's general wishes regarding aggressiveness of therapy. Later discussions may cover more specific topics such as resuscitation, intubation, transfusions, artificial feeding methods, and site of death.
In palliative medicine, the usual roles of the physician and patient are exchanged. It is the patient who chooses the therapy, and it is the physician's major duty to satisfy the patient's demands (7). Roy (16) states that the governing idea of palliative care has been the enhancement of humanization over any trend to reduce a suffering person to impaired organ systems. He calls palliative care an evolving medical discipline which represents a new movement and mobilization of human consciousness. It is an attempt to challenge how traditional medicine splits the mind from the body, cure from care, patient from family, family from society, and scientific objectivity from human compassion. Latiner (14) states that palliative care centers on the patient as an individual, fostering autonomy and choice in matters of care, and meeting the person on his or her terms, acknowledging the inherent worth and dignity of each person.

Wanzer et al (17) emphasize the importance of deliberately creating a medical environment that allows a peaceful death. The physician must formulate a flexible and adjustable care plan, tailoring treatment to the patient's changing needs as the disease progresses. This group of physicians states that as death approaches, dying patients may require palliative care of an intensity that rivals even that of curative efforts. Intensive measures may be necessary, including keeping the patient clean, caring for the skin, preventing the formation of bed sores, treating neuropsychiatric symptoms, controlling peripheral and pulmonary edema, aggressively reducing nausea and vomiting, using intravenous medications, and fighting the psychosocial forces that can lead to family fragmentation.

Twycross (9) provides three points to consider when deciding what treatments are appropriate for the dying
patient: (1) the patient's biological prospects; (2) the therapeutic aim of each treatment; and (3) the need not to prescribe a lingering death. To this author, the art of medicine is to decide when sustaining life is essentially futile, and when to allow death to occur without further impediment. For example, antibiotics are usually appropriate for the patient with advanced cancer who develops a chest infection while still relatively active and independent. However, pneumonia should still be "the old man's friend", and if the burden of living has become considerable, then it may be more appropriate not to use antibiotics. Twycross emphasizes that rehabilitation is part of terminal care, meaning that a patient must be helped to achieve her maximum potential physically, emotionally, socially, and vocationally. An attentive physician should provide both symptom control and gentle encouragement to the patient.

Hesketh (10) states that palliative care encompasses at least four components: (1) cancer therapies; (2) palliative technical procedures; (3) control of pain and other physical symptoms; and (4) psychosocial and spiritual support of the patient and family. The remainder of this chapter will discuss the third component in greater detail.

Pain and Suffering

Many authors emphasize how pain is the symptom most feared by dying patients and their families, and how pain is often undertreated (6,8,18,19,20). Cancer pain can appear to be unending, except by death. It is usually constant, worsening in severity, and associated with other unpleasant physical symptoms such as anorexia, vomiting, or dyspnea (8). Angell (18) calls pain "soul destroying". The life of
a patient with chronic pain becomes organized around avoiding or treating pain, rather than making the most of remaining time. The patient may feel that the discomfort will never go away and is constantly reminded of his impending deterioration and death (20).

Cartwright et al (21) report that 87% of cancer patients had pain in the last year of life. Foley (22) reports pain in 85% of primary bone tumor and 52% of breast cancer patients, compared to only 5% of cases involving leukemia. Foley (23) also found that moderate to severe pain occurs in one-third of cancer patients receiving active therapy and in 60 to 90% of patients with advanced disease. Wilkes (24) studied 600 patients and found pain to be present in 82% of patients with cervical cancer, 75% with gastric cancer, and 44 to 59% with cancer of the lung, rectum, or breast. Bonica (25) analyzed 32 published reviews and concluded that 70% of patients with advanced cancer suffer significant pain. The reports also suggested that 50 to 80% of patients do not have satisfactory pain relief.

The subject of pain associated with cancer is very complex and an in-depth discussion is beyond the scope of this dissertation. Briefly, cancer pain can be defined by its temporal aspects as acute, chronic, or incidental; or on the basis of its physiologic mechanisms as somatic, visceral, or neuropathic (26). According to Foley (27), there are three major categories of pain syndromes: pain associated with direct tumor involvement; pain associated with cancer therapy; or pain not related to the cancer or the cancer therapy.

Suffering is a symptom which is related to pain, and the word "suffering" is often coupled with the word "pain". Suffering can include physical pain, but is by no means
limited to it. Suffering extends beyond the physical, and involves all aspects of a person, body, mind, and spirit. Suffering is ultimately a personal and subjective matter. People in pain frequently report suffering from the pain when they feel out of control, when the pain is overwhelming, when the source of the pain is unknown, when the meaning of the pain is dire, or when the pain is chronic (28).

Any illness causes anxiety, especially one that becomes more serious despite a variety of treatments until it is clearly life-threatening. Physical distress enhances mental suffering, and mental pain may be compounded by spiritual issues. A patient may experience social pain since he is part of a family unit. Social pain can include grief, guilt, fear, family tensions, and lack of communication. Pain can be spiritual, and patients can have feelings of guilt, worthlessness, or meaninglessness (29). Mental and emotional conditions, such as anxiety, depression, insecurity, and fear can make physical pain worse (20).

Cassell (28,30) emphasizes that the relief of suffering and the cure of disease must be seen as twin obligations of the medical profession. Physicians' failure to understand the nature of suffering, and to recognize its presence in the patient, can result in medical intervention that is technically adequate, but does not relieve suffering, and becomes a source of suffering itself.

Pain Control

Much of the literature describing palliative care is devoted to the subject of pain control. As described
previously, pain is present in the majority of terminal patients, especially those with cancer, and is the symptom most feared by patients and their families. Many experts agree that the terminally ill patient must have whatever is necessary to control pain (8,17). The challenge to the health care provider is to assess the pain problem early, provide adequate interventions, reassess effectiveness frequently, and always be ready to try something else (31). Pain must be relieved as soon as it becomes a matter for complaint (32).

The World Health Organization (WHO) Cancer Pain Relief program has advocated the use of an analgesic ladder as a guide to the management of cancer pain (33). This approach starts with nonopioid drugs, such as acetaminophen and the nonsteroidal anti-inflammatory drugs (NSAIDs) for mild to moderate pain; graduates to the use of weak opioids, such as codeine or oxycodone; and culminates in the use of strong opioids, such as morphine. Patients with severe pain are treated initially with a strong opioid. At each step of the ladder, adjuvant analgesics may be used. Adjuvant analgesic drugs include anticonvulsants, phenothiazines, antidepressants, antihistamines, steroids, antibiotics, amphetamines, muscle relaxants, and butyrophenones (34,35).

Oral morphine is the standard for comparison and is the drug of choice for chronic severe pain (32,36). Other routes of administration are intramuscular, intravenous, subcutaneous, sublingual, buccal, rectal, spinal, and transdermal. The administration of drugs for cancer pain is a complicated topic which is beyond the scope of this dissertation. Nutrition-related side effects of some commonly used drugs will be discussed in Chapter 3.

In addition to drugs, several nonpharmacological interventions are available for cancer pain relief. These
may include relaxation techniques, imagery, distraction, biofeedback, acupressure, therapeutic touch, and peripheral nerve stimulators (37). Radiation therapy may be helpful, if given without delay, in the minimal possible number of treatments, and if it has been determined that the benefits to the patient outweigh the inconveniences involved (35). Radiotherapy might be appropriate for treating bone metastases, brain metastases, spinal cord compression, or obstructions in the airway, ureteral, or lymphatic systems caused by tumors (10,35). Chemotherapy and hormonal therapy may also be considered for such problems caused by tumors which are chemo-sensitive or hormone dependent (35). Nerve blocks may also be effective for pain, depending upon the site of the pain and the general condition of the patient (35). Surgery can be used to relieve symptoms associated with mechanical obstruction, actual or impending pathological fractures, or relief of symptomatic effusions (10).

According to Saunders and Baines (35), experiences from hospices in the UK show that 85% of cancer patients have their pain satisfactorily and relatively easily controlled. A further 10% prove more difficult, requiring frequent alterations of the drug regimen and perhaps non-drug methods to maintain control of pain. In the remaining 5%, pain control is not satisfactory, and may be due to severe but intermittent pain; a short time or poor compliance with treatment; or major emotional or family problems.

**Control of Other Symptoms**

A wide variety of symptoms are experienced by patients with advanced cancer, and no one symptom occurs in every patient (9). Symptoms are caused by many factors (9,38).
The malignant process, including the primary tumor and metastases, may produce symptoms by distorting the organs involved or adjacent organs. Symptoms can be produced by past or present cancer treatment or treatment to palliate a primary symptom. Other symptoms arise from any of the multiple metabolic changes which occur in advanced cancer, or from a concurrent second disorder. It is necessary to identify the different factors involved and then seek to correct those that are reversible (9).

Lichter and Hunt (39) studied the problems that arose during the last days in the lives of 200 terminally ill cancer patients. Results showed that 36% of patients experienced some problems in the last 48 hours of life. The majority of patients (91.5%) died peacefully. Factors that interfered with a peaceful death in the remainder of the patients were hemorrhage and hemoptysis, respiratory distress, restlessness, pain, myocardial infarction, and regurgitation. The symptoms observed in the last 48 hours of life were pain (51% of patients); dyspnea (22%); noisy and moist breathing (56%); nausea and vomiting (14%); confusion (9%); restlessness and agitation (42%); muscle twitching and jerking (12%); urinary incontinence (32%); urinary retention (21%); and sweating (14%). The authors also found that 30% of patients were conscious until death; 38% became unconscious 0 to 12 hours before death; 24% became unconscious 12 to 24 hours before death; 7% became unconscious 24 to 48 hours before death; and 1% were unconscious for more than 48 hours.

Morris et al (40) studied the quality of life of terminally ill cancer patients during the last thirteen weeks of life. The authors found that declines in the quality of life varied as a function of the patient's proximity to death, with rapid decline being limited to the
last one to three weeks of life. Twenty percent of patients did not exhibit a low quality of life, even in the week before death. Pain was the most common severe symptom, occurring in slightly less than 50% of patients. Ventafridda et al (41) studied 120 terminal cancer patients in palliative home care. The intensity of symptoms was assessed by an endurable/unendurable scale as reported by the patient. During the entire period of home care for all patients, there were 123 episodes of symptoms characterized by the patients as unendurable (pain, 60% of episodes and dyspnea, 40%). The majority of patients had either dyspnea (41%) or pain (39%), with few patients experiencing delirium (14%) or vomiting (6%). The authors concluded that more than 50% of patients with terminal cancer will die with physical suffering that can be controlled only by sedation, and that the onset of unendurable and uncontrollable symptoms was a good prognostic indicator of imminent death.

Peruselli et al (42) identified the prevalence of physical, functional, psychologic, and social problems in patients receiving palliative home care, as reported in the ongoing records of nursing diagnoses. Their subjects were 40 terminally ill cancer patients receiving home health care for a period of one to 19 weeks. The patients ranged in age from 34 to 84 years, with a mean age of 65.9. The authors used nursing diagnosis records for the patients, and identified more than 697 nursing diagnoses. Also, 15 of the 40 patients were able to complete a weekly self-report of their symptoms and the degree of intensity for each symptom. Results showed that the most frequently reported nursing diagnoses were anxiety (9.5%), constipation (9.2%), diminished food intake (8.6%), noncompliance with physical activity (5%), and coping potential of the family (4.9%). When the patients' descriptions of their symptoms were
compared with the symptoms identified by the nursing staff, there was agreement in 63% of cases.

According to Turnbull (38), it is important to diagnose the cause of each symptom in order to rationally manage that symptom. Diagnosis is based on a careful history and on clinical examination. Usually, any specific investigative procedure is not of much value and does not significantly alter the patient's management. When it is impossible to accurately diagnose the cause of a symptom, it is rarely justified to withhold treatment until the etiology is established.

Twycross (9) emphasizes that if the physician is dealing with a persistent symptom for which pharmacological measures are appropriate, drugs should be prescribed regularly on a prophylactic basis. This advice is increasingly adopted for pain control, but also applies to the use of such drugs as antiemetics and laxatives. This author agrees with many others that the use of drugs "as required" instead of regularly is the cause of much unrelieved distress.

Doyle (43) distinguishes between the significance of the presence of a symptom in the dying patient and its significance in acute medicine. In acute medicine, a symptom is elicited from the patient, or is volunteered spontaneously, and helps the physician make a diagnosis. The patient's symptomatology is also fairly fixed because the illness tends to be of short duration. Generally, acutely ill patients gladly tell about their symptoms. In chronic conditions, however, and especially in the terminal patient, many symptoms are borne in silence and tolerated. The patient feels that a symptom is of no help to the physician, is unlikely to change the course of his illness, and perhaps nothing can be done about it. A symptom has no
diagnostic, therapeutic, or prognostic significance, is a measure of the patient's suffering, and is a reminder of a condition for which a cure cannot be found.

Doyle (43) describes three main effects that symptoms have on patients. Certain symptoms can frighten patients (pain, dyspnea, dysphagia, hemorrhage, panic, paralysis, convulsions); distress patients (incontinence, anorexia, depression, constipation, vomiting, pruritis, confusion); or isolate patients (paranoia, odor, halitosis, ugliness, insomnia, sweating, personality change). He emphasizes that the health professional must discuss and explore symptoms and discover the significance of each to the patient. It is also important to define to the patient those symptoms which can be controlled, and those which cannot, because what is unknown causes fear. Doyle provides four basic rules for symptom control: (1) nothing is trivial, and everything is worth recognizing and discussing when one is dying; (2) not all distresses demand or require treatment; many patients are grateful to express their feelings and fears to someone who is willing to listen, and do not always expect a prescription for each symptom; (3) the pathology causing a patient's symptoms is a dynamic process, symptoms keep changing, and constant review is necessary; and (4) one cannot separate the physical, emotional, social, and spiritual dimensions of human life.

Many sources contain detailed information on treatment methods to control the common symptoms experienced by the terminal cancer patient. These treatments will not be reviewed here. Common symptoms mentioned by authors (31,38,44,45,46) include: nausea and vomiting; anorexia and cachexia; dehydration; diarrhea and constipation; delirium; depression, anxiety, and fear; dyspnea; urinary retention and incontinence; pressure sores; malignant intestinal
obstruction; dysphagia; neuromuscular dysfunction; malignant ulceration; thirst; dry or sore mouth; fatigue; odor; pruritis; hiccough; cough; airway secretions; confusion; insomnia; epileptiform convulsions; weakness; hemorrhage; anemia; belching; dysgeusia; fever; fluid accumulation; halitosis; heartburn; hypercalcemia; jaundice and hepatic encephalopathy; and stomatitis. As mentioned previously, treatment methods for symptoms can include drugs, surgery, chemotherapy, radiotherapy, hormone therapy, relaxation techniques, etc.

Some simple treatment methods for meeting the personal care needs of terminal patients are mentioned by Moseley (31). These include skin care (cleansing, baths, back rubs); mouth care (remove dry saliva and mucus, keep lips lubricated); hair care (shampoos); eye care (artificial tears, eye ointments, cleanse eyes); and positioning to reduce fatigue and to increase comfort and relaxation.

Regardless of the underlying pathology, it is cardiopulmonary failure that is the final cause of death. Thus, the best indicators of imminent death are cardiac and respiratory signs (1). Zerwekh (47) lists the major signs and symptoms which occur as death is imminent: cessation of eating and drinking; oliguria and incontinence; difficulty in breathing; cyanosis; decreased mental alertness; and changes in vital signs, including a decrease in body temperature, an increase in rate and irregularity of the pulse, a rise and then a drop in respirations with an increase in the number and lengths of periods of apnea, and a fall in blood pressure. The New River Valley Hospice (48) has prepared an information sheet for caregivers listing "Signs of Approaching Death and Comfort Measures". In addition to the previous signs and symptoms, the hospice lists: an odor, especially if cancer and/or lung
complications are present; increased sensitivity to light; confusion about time, place, and identity of family and friends; talking out loud with someone who has already died; a glazed look in the eyes; sleeping with the eyes only partially shut; and sweating while arms and legs remain cold. Death is defined as the last inhalation (1).

The Hospice Concept

Phipps (49) reviews how hospice is an ancient tradition dating back at least 2,000 years. In ancient Greece, sick persons in the eastern Mediterranean could find temporary shelters at the temples of Asclepios, the Greek god of healing. Hospitals began in the early Christian era to follow the doctrines of Jesus emphasizing love and pity. Constantine decreed in AD 335 that nosocomia (infirmaries) be erected in Roman cities. Around this time, the sick and dying were cared for in many Mediterranean cities. The term "hospitium" began to be used to refer to a place where travelers and the infirm were kept by Christians expressing their humanitarianism. The words "hospice", "hospital", "hostel", and "hotel" are all derived from the same Latin root and all once had the same meaning. Later, Benedictine "hospitallers" ministered to a wide variety of needy people, including the ill, the homeless, the poor, and prisoners. Charlemagne encouraged monasteries and cathedrals to attach hospices to their institutions. About 100 years ago, Augustinian monks founded St. Bernard's Hospice in the Swiss Alps to provide refuge for the needy. Since then, many religious orders founded hospices throughout Europe.

In the 20th Century, the hospice movement began with the establishment of St. Joseph's Hospice in London in 1905. The hospice concept was reintroduced and expanded by Cicely
Saunders who founded St. Christopher's Hospice in 1967 in England. The first American hospice was begun in New Haven, Connecticut in 1974. In 1980, the Joint Commission on Accreditation of Hospitals surveyed health care agencies across the US, and identified more than 800 programs in various stages of development and function (50). By 1990, there were more than 2,000 hospice providers in the US (10).

The National Hospice Organization (51), which represents the majority of American hospices, defines hospice as a centrally administered program with palliative and support services which provides physical, psychological, social, and spiritual care for dying persons and their families. Services are provided by a medically-supervised, interdisciplinary team of health care professionals and volunteers. Hospice services are available in both the home and inpatient settings. Home care is provided on a part-time, intermittent, regularly-scheduled basis, and is available on an on-call basis, 24-hours per day. Bereavement services are available to the family, and admission is on the basis of patient-family need.

The vast majority of patients in hospice care have a diagnosis of cancer, but other patients, such as those with Acquired Immune Deficiency Syndrome (AIDS), are also eligible for care in many hospice organizations (10). Admission to most hospices requires that the terminally ill patient have a life expectancy of three to six months (52). Although hospices vary greatly in size and organizational structure, they share a common philosophy that begins with the notion that "death is part of life", that there comes a point in medical care when cure is no longer a possibility, and attention must focus on comforting patients and families. This comfort involves both symptom relief and human social support. The goal of medicine is redirected
from cure to palliation, implying that medical care must be 
construed broadly and provided by people with many different 
skills (50). The hospice team is guided by the patient and 
by their philosophy of allowing the patient to actively live 
until he dies, emphasizing quality, not quantity, of life 
(53).

McCue (54) discusses how the acceptance of the 
naturalness of dying directly conflicts with the 
medicalization and the legalization of death that 
characterizes modern society's treatment of dying patients. 
He explains that most health care providers believe that 
dying results from disease and injury which may yield to 
advances in medical technology. He states that to offer 
more humane medical treatment to dying patients, and to 
improve communication among patients, families, and 
physicians, the narrow biomedical view of dying must be 
rejected, and some of the palliative and healing skills 
prevail before the birth of modern scientific medicine 
should be relearned. He calls on physicians and nurses to 
amsume the role of medical stewardship to help prevent the 
overreatment and overtesting of modern medicine's approach 
to the dying.

Greer (55) reviews some recent demographic and social 
trends which aided the growth of the modern hospice 
movement. First, more of the dying are older, and suffer 
from chronic illnesses, causing changes in family 
relationships to the dying patient. Second, dying has 
shifted from the home to hospitals and long-term care 
facilities, and the dying process has been dominated by 
professionals and their technology. Society is becoming 
dissillusioned with technology in general, and some of its 
negative results. Third, in the past, while many persons 
accepted suffering while expecting reward in the afterlife,
recent trends focus on the good life here and now. Medicine has been forced to consider quality of life issues as part of its mandate. Fourth, beginning with the publicity of Kubler-Ross's "On Death and Dying" (56) in 1969, the dying process has begun to be seen as an important part of living, worthy of the attention of both professionals and laypersons. Finally, American social activism and aggressive consumerism has led to an emerging trend for increasing numbers of people not being prone to defer to professional opinion or expert advice.

Tehan (57) explains how many of the early hospice programs evolved from an antimedical perspective espoused by their founders. In their view, dying patients were not being adequately cared for by the traditional health care system, and hospice was seen as the solution. Others saw hospice as giving patients an alternative to the traditional cure-oriented system. Many hospices were developed by idealistic, nonmedically trained individuals and were largely separate from the health care system, especially the volunteer-based community hospices. The care for hospice care was made by educating physicians, the public, and health care professionals about how the needs of dying patients could be more adequately met, and that palliative care was a sophisticated and skilled professional intervention. Buckingham (58) states that the hospice concept represents a return to humanistic medicine, to care within the patient's community, for family-centered care, and the view of the patient as a person. Since hospice uses no sophisticated diagnostic and treatment equipment, but rather personal care and medicines, the patient is permitted to die with dignity.

Lamer's (59) provides some additional factors which he believes played a role in the rapid acceptance of the
hospice concept. First, the cost of dying has escalated along with advances in science and technology. Hospice offers the economical use of home care and volunteers without a sacrifice in the quality of care or quantity of life. Second, cancer therapies, while sometimes offering cure or relief, have debilitating side effects. Hospice offers an alternative setting for patients for whom further therapy only aggravates an already impaired quality of existence. Third, statistics show that each year, one million new cancer cases are diagnosed, and one-half million persons will die of cancer. People can no longer distance themselves from death when friends or family members face death by cancer, and they become vulnerable. Caregivers must care for the dying, and also see that survivors get support. Fourth, since patients with advanced cancer often suffer "unendurable" chronic pain, and curative medicine often treats it poorly, the multi-modality approach to pain control used by hospice is of great benefit to cancer patients. Finally, hospice is effective because it considers the patient as a total person in all dimensions, physically, socially, psychologically, spiritually, and economically, and regards the family as part of the unit of care.

Magno (60) considers the three main problems that hospice addresses as pain, loneliness, and loss of control. The patient and family are assured that pain can be controlled; the patient and family are given loving care and attention as needed during the dying process, and afterward; and the patient is treated as a person who is allowed to make decisions about his own care.

Brescia et al (61) conducted a retrospective study of patients who died in a home care hospice program during a six-month period. Their purpose was to evaluate quality of
palliative care and to understand the differences between patients who die at home and those who die in the hospital in a well-designed hospice setting. During the six-month period, 50 patients died, with 36 dying at home and 14 in the hospital. Among the 50 patients, 45 (90%) had cancer of different types, and their average age was 68.2 years (range 48-88). The average patient's stay in the program was 37 days (range 2-180). Pain was the single most important symptom complex recorded that made hospitalization necessary. All of the five patients who did not have cancer died at home. Only 2 (6%) of the 36 patients who died at home were recorded as denying their illness, while 29% of the hospital deaths showed signs of nonacceptance to the staff. There was a tendency for younger patients to die in the hospital.

The authors found that among the patients who died at home, there was no symptom complex which was perceived as unmanageable by the patients' family, nurse, or physician. The authors were unable to predict which patients would be able to die at home in this study, and found that the only variables that might have some import were the patient's age and whether he had accepted the illness.

Mor and Masterson-Allen (62) present data from the National Hospice Study describing attributes of hospice care in America. Males and females are approximately equally represented as hospice patients, and the large majority are white. Unlike nursing home patients who tend to be over 75 years of age, the hospice patients are "young-old", in their mid-to-upper 60s. Over 90% of patients have cancer.

It was found that three types of hospice organizations have evolved: (1) hospices affiliated with hospitals, with or without a home-care component; (2) hospices affiliated with pre-existing home health agencies without their own
inpatient unit; and (3) "freestanding" hospices, exclusively serving terminal patients, with or without a special inpatient unit.
REFERENCES


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45. Ibid. 55-68.


Chapter 2: Nutrition Care

According to the American Dietetic Association (1), the dietitian must be flexible in attempting to meet the nutrition needs of a dying patient. This professional association states that it might be more useful to emphasize the provision of emotional support and TLC (tender loving care) than to concentrate on providing the RDAs (Recommended Dietary Allowances). This chapter describes some general guidelines for the nutrition care of the terminal patient. Emphasis is placed on feeding by mouth (artificial feeding is covered in Part IV) and on the care of the patient at home, not in a hospice inpatient unit. The nutrition of the terminally ill patient is a subject which can be approached from medical, legal, religious, and ethical points of view. This chapter emphasizes the medical care aspects of feeding the terminal patient, and Chapter 8 discusses ethical considerations.

Goals of Nutrition Care

Each patient is an individual with unique needs and wishes, so there can be no hard or fast rules in the nutrition care of the terminally ill (2). Nutrition support for terminal patients requires the dietitian to change the focus of care from improvement in the patient's nutrition status to more palliative measures of patient comfort (3). The provision of nutrition care must be highly individualized and must recognize the wishes of the patient. Also, nutrition care must be evaluated in terms of greatest benefit and least risk to the patient (4). Care must be taken that no food is given that might either worsen the condition or disagree with the patient, while at the same time, an attempt should be made to provide foods
that are well liked (5). It must be recognized that identifying malnutrition is prudent in palliative care, but reversing malnutrition may not be possible or appropriate in terminal patients (6).

Maillet and King (7) state that the principle goals of palliative nutrition care are to maximize the patient's nutrition benefit, pleasure, and comfort from food while minimizing discomfort. Common discomforts which contribute to decreased food and fluid intake and to decreased nutrient absorption might include pain, shortness of breath, depression, weakness, anorexia, vomiting, diarrhea, and gastrointestinal obstructions. Billings (8) mentions that reasonable nutrition goals include: (1) comfort, well-being, and pleasure in eating; (2) preventing gross malnutrition, supplementing deficient diets, maintaining weight when practical, and rarely, slow rebuilding of body mass; and, (3) treating or preventing specific symptomatic nutrition abnormalities, such as fat malabsorption or hyperkalemia.

Psychosocial Factors in Nutrition Care

According to Gallagher-Allred (9), hospice patients are unique in their ethnic and cultural food preferences, food preparation methods, desired times for meal service, persons allowed to provide food, and even order of foods eaten. Hospice patients also have many characteristics in common. Ninety percent of hospice patients have cancer as the primary diagnosis, and often exhibit symptoms such as anorexia, cachexia, nausea, vomiting, constipation, or diarrhea. Approximately 60 to 80% of hospice patients require some type of diet modification. Gallagher-Allred emphasizes the need for the dietitian to deal with both the common and unique characteristics of hospice patients and
their families.

Weddle et al (10) state that lifetime food-related behaviors can assume far-reaching social, religious, and philosophical meanings. For the elderly hospice patient, foods associated with religious practices and rituals can be a source of comfort, continuity, and stability, and provide a focal point for patient-family interaction. Maillet and King (7) state that terminally ill patients and their families need honest, open communication about what nutrition and feeding can do, and about the best possible nutrition care and available resources. The dietitian should explain the relationship between intake and symptom management, and the symptoms that may result from not eating.

Stephany (11) states that teaching family members that it is "normal" to lose one's appetite in the dying process is one of the hospice nurse's toughest jobs. Most patients desperately want to please their caregivers, but have no appetite. Patients force themselves to eat, and often feel bloated and/or nauseated as a result. Some family members will never give up their quest to feed the patient. Billings (8) says that the health care professional must identify the personal reactions of the patient and family to poor intake, weight loss, and cachexia. Many patients and families place very high significance on eating regularly and well, and they overrate the importance of nutrition for a person who is severely debilitated and will die soon regardless of intake. Family members may become very upset if a few meals are rejected, believing that the patient will starve or die quickly. They may not be aware that a patient can survive for long periods of time with little intake or that a liquid diet can provide adequate nutrition.
Gallagher-Allred and Amenta (12) emphasize how food and feeding are a central element and an organizing principle in family life. When a family member becomes sick, the issue of feeding and eating takes on great significance. When the sick and dying person cannot or will not eat, it can be interpreted as a sign and reminder that life is ebbing; that the family is losing an essential person in its social system; and that the caregiver who prepared the food and urged the feeding is losing her role as nurturer and her job as caregiver. These authors urge health care professionals to help patients and families learn to prepare special foods and learn ways of adapting to the dying process that can still provide the pleasure, nurturance, and sense of control that food and feeding have had for the family and the patient. Patients who want to eat should be fed and hydrated, while patients who cannot eat should be provided support in other ways.

**General Guidelines for Providing Nutrition Care**

When working with any patient, the dietitian should assess the situation, formulate a plan of care, implement the plan, and evaluate its effectiveness. Several authors explain how these steps can be accomplished in palliative nutrition care.

Gallagher-Allred (13) suggests starting a nutrition assessment by screening the patient and family. This is best accomplished by participating in the hospice interdisciplinary team meetings in which patient and family goals are discussed, and it can be determined if and how the dietitian can be of benefit to the patient and family. If the results of the screen indicate a need for nutrition intervention, the dietitian should obtain more information from the patient and the family including: patient's ethnic
status and socioeconomic background; patient's ability to perform activities of daily living (ADL's); patient's level of pain; patient's prognosis; how the patient and family members are handling the dying process; the palliative care goals; and patient medical care plan. Gallagher-Allred (13) emphasizes that some parameters that are appropriate assessment tools for non-terminal patients may not be appropriate tools for the terminal patient. Laboratory assessment of visceral protein status, anthropometric measurements, immune function tests, and biochemical studies are rarely important in terminal patients. Rather, dietary assessment and the assessment of possible nutrient and drug interactions are frequently important. The rationale for performing a particular nutrition assessment parameter should be based on whether the result will make a difference in palliative treatment.

Wade and Jain (15) suggest that the dietitian determine the patient's diet acceptance and food intake and construct a diet history, with the goal of guiding the patient in adjusting his food intake to maintain adequate nutrition and to prevent or minimize further weight loss. The American Dietetic Association (1) suggests that the dietitian review any nutritionally relevant objective data, including the physician's prognosis, medical diagnosis, symptoms and sources of discomfort, previous treatments, any modified diets, and medications. Other relevant information might include the patient's religious, philosophical, social, emotional, and financial concerns that affect dying. The association also mentions gathering subjective data about the patient, including her ability to ingest food; presence of dysphagia, nausea, vomiting, discomfort, and pain; and if she is requesting special foods or refusing all food.
From the information obtained from the nutrition assessment, the dietitian can formulate a nutrition care plan for the hospice patient. Gallagher-Allred (13) mentions the dietitian's major responsibilities in the care plan: to suggest nutrition techniques that will be helpful in symptom and pain control; to anticipate those problems most likely to occur; and to guide the patient and her family in making plans to prevent these problems from occurring. The dietitian should provide: knowledge of how the disease process and the dying process can affect the patient's desire for food; knowledge of how changes in the patient's appetite and ability to eat can cause changes in food intake, bodily appearance, and bodily function; knowledge of specific dietary measures for symptom control; knowledge of relief measures that will be available as the patient's condition deteriorates; use of community nutrition and food resources as needed; and knowledge of how to reach the dietitian when questions arise and nutrition assistance is needed. The American Dietetic Association (1) emphasizes the importance of presenting sufficient information about the care plan to the patient and caregiver, and assuring that the care plan reflects the choices and wishes of the patient. Also, communication with other members of the interdisciplinary care team is required.

Several authors provide some general measures to use when formulating a care plan for terminal patients. Matthews (4) states that the dietitian's recommendations and treatment plan should reflect three things: the patient's medical status, needs, and wants. For example, if the patient has impaired chewing or swallowing, which limits food choices, and chooses to fight the disease and maintain strength, then high-calorie, high-protein
milkshakes, supplemental feedings, puddings, or even a nasogastric feeding, may be appropriate, if this is what the patient wants. If certain foods bring comfort, such as favorite desserts or traditional ethnic foods, then every effort should be made to supply these foods to the patient.

According to some authors (4,7,15,16), long-standing dietary restrictions based on rationales for preventing and treating chronic disease should not be imposed, except when they alleviate physical discomfort. For example, diets restricting energy for diabetics, or sodium and cholesterol for preventing or treating cardiovascular disease should be discontinued unless ignoring such restrictions worsens symptoms or hastens death. Also, the hospice dietitian must frequently update the nutrition care plan as the patient's symptoms and conditions fluctuate (7).

Maillet and King (7) mention some other factors to consider in formulating the nutrition care plan: access to food; the strength to prepare meals; the purchasing of foods; the use of governmental and private home delivered meal programs; and the patient's taste and smell acuity, which might influence types of food and site of preparation. Kidd and Lane (15) mention that the dietitian must gain knowledge of the patient's ethnic, cultural, and regional food preferences; daily meal pattern; opportunities for re-heating items for preparing a quick meal; and fluctuations in mental alertness, level of responsiveness, dental status, and swallowing difficulties. Kidd and Lane (15) recommend simple, easy-to-prepare foods served in smaller portions, and the use of "comfort" or familiar foods. They mention some commonly selected comfort foods as: macaroni and cheese, grilled cheese sandwich, peanut butter and jelly sandwich, meatloaf, soup, fresh fruit, and salads.
After the nutrition care plan is formulated, it should be implemented. According to Gallagher-Allred (13), generally the patient and family are pleased to receive nutrition guidance, and accept suggestions enthusiastically. She suggests that the dietitian follow proven communication and counseling techniques to promote increased patient and family understanding about how to implement the care plan. The dietitian should also answer questions in an honest, open, and trustworthy manner. Arnold (3) states that patients should be encouraged, not forced, to eat and drink as much as they desire. Gallagher-Allred (17) states that families should consider it a blessing when terminal patients eat when it is enjoyable for them, and mealtimes should be shared with loved ones. She emphasizes that eating should maximize enjoyment and minimize pain, and if eating is not an enjoyable experience for the patient, its practice should not be overemphasized.

Finally, the effectiveness of the nutrition care plan should be evaluated, so that progress can be noted, and the care plan can be modified as necessary. Gallagher-Allred (13) emphasizes the importance of medical record charting by the dietitian as a means to keep all team members apprised of a patient's situation; to document responses to palliative care measures; and to evaluate the achievement of palliative care, including nutrition.
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KEY ISSUES DISCUSSED IN PART I:

- A patient is considered "terminal" when he has a life expectancy of six months or less.

- Most physicians and health care professionals are not trained in palliative care in which symptoms, not diseases, are treated.

- Effective palliative care as provided by hospice treats the patient as a human being, with physical, mental, emotional, psychologic, and spiritual components. Optimal palliative care requires an interdisciplinary team effort.

- Some common symptoms to be controlled in the terminal patient are pain, nausea, vomiting, breathing difficulties, urinary incontinence, anorexia, constipation, anxiety, and depression.

- The principle goals of palliative nutrition care are to maximize the patient's benefit and pleasure from food while minimizing uncomfortable symptoms.

- Each patient is unique in their food preferences and food intake, and any nutrition care plan must reflect the choices and wishes of the patient.
PART II. NUTRITION AND THE CANCER PATIENT

Introduction:

There are many complex interrelationships between nutrition and cancer in humans. A large body of research has investigated the relationships between the intake of various foods and nutrients and the development of tumors. However, the role of nutrition in the etiology of cancer will not be reviewed as part of this dissertation.

Other research has explored the relationship between nutrition and cancer which is already present. Investigation falls into two broad categories: the effects of the presence of cancer on the patient's nutrition, and the role of nutrition in the cancer patient's prognosis and treatment. Literature devoted to these two areas will be reviewed.

Chapter 3. The Effects of Cancer on Nutrition

Cancer is a generic term used for a group of some 250 diseases characterized by uncontrolled growth and spread of abnormal cells. If the spread is not controlled, it can result in death. In the early 1900's, few cancer patients had any hope of long-term survival, and cancer was considered an acute terminal disease. But at the present time, because of advances made in the diagnosis, treatment, and management of cancer, about four of ten patients who get cancer in 1994 will be alive five years after diagnosis (1,2). Today, many cancers and their associated symptoms are considered chronic illnesses which can be treated
outside the hospital (2,3).

The cancer symptoms discussed in this section are chronic, ongoing symptoms that increase or decrease in magnitude relative to the progression of the cancer or to its treatment regimen. Patients are likely to experience many symptoms which frequently interact with one another to present a very complex clinical picture. Also, it is often impossible to single out one cause of a symptom (3), and symptoms often interrelate to each other (4). For example, symptoms of anemia, breathing difficulties, and the accumulation of waste products from cell destruction due to radiotherapy can all contribute to the overall symptom of fatigue (4).

Many sources list symptoms which result from cancer, and their possible causes. Physical symptoms experienced by the cancer patient may arise from physiological, biochemical, metabolic, and/or hormonal changes which occur as a result of the disease, or from the treatment method(s) used. These patients frequently have a poor appetite, absorption of foodstuffs may not be normal, the utilization and metabolism of absorbed foodstuffs may be altered, the metabolic rate may be elevated through various mechanisms, and the cancer treatment method may further impair nutritional maintenance (5). There are also psychological and social factors which affect food intake of cancer patients dealing with a serious and debilitating disease.

The topic of the nutritional effects of cancer in humans is extremely complex, and this review will focus on the symptoms and conditions which most greatly affect food intake. Also, attempts to separate these symptoms from one another are artificial.
Cachexia

According to Daly et al (6,7), the term cancer cachexia describes a group of symptoms and signs that encompass inanition, anorexia, weakness, tissue wasting, and organ dysfunction. Cachexia is common in patients with advanced metastatic disease, but also occurs in patients with localized disease. The relationship of cachexia to tumor burden, disease stage, and cell type is inconsistent; no single theory satisfactorily explains the cachetic state. A variety of etiological factors can occur simultaneously or sequentially to produce cachexia. Also, numerous studies have documented abnormalities of host metabolism which together indicate that cancer cachexia is not the same as simple starvation (8).

According to Holroyde and Reichard (9), of the factors associated with cancer cachexia, weight loss is usually the most obvious, with wasting of body fat and lean body mass, presumably due to an imbalance between energy intake and energy expenditure. It is often unclear whether the weight loss of malignancy results from a decreased energy intake, increased energy expenditure, or a combination of both. These authors also emphasize that the incidence and severity of weight loss bear no precise relation to the size, site, stage, or histology of the tumor. Costa (10) describes the patient with cachexia as appearing chronically ill, and often emaciated, with pale skin, edema, ulcerations, fractures, and sometimes abnormal drainages. Cachexia progressively alters vital functions, and can eventually lead to death.

Fearon and Carter (11) state that, in spite of the vast literature on the subject, the mechanisms by which tumors produce the symptoms of cachexia remain unknown. This is due mainly to a lack of systematic studies of the
problem. Patient studies have been carried out on small numbers, and often the results are not generally applicable. Also, many patients have already undergone some form of therapy or are at different stages in the development of cachexia. The authors believe that comparisons between studies is often impossible; thus, the literature contains confusing and contradictory results.

Cancer cachexia is so common that 50% of cancer patients have symptoms and signs of cachexia at the time of initial diagnosis (12-14). DeWys et al (14) noted substantial weight loss in 40% of patients with breast cancer and in 80% of patients with gastric or pancreatic cancer.

Cancer cachexia is a complex phenomenon which authors usually describe by listing symptoms and conditions associated with it, such as weight loss; anorexia; abnormalities in protein, fat, carbohydrate, and energy metabolism; local tumor effects; psychological factors; and effects of therapy. All of these subjects will be covered briefly in this review. Figure 1 illustrates some of the causes and effects of cachexia.

Anorexia

Anorexia, or loss of appetite, is a major contributing factor in the development of cancer cachexia. However, the exact mechanism of anorexia is still unknown (15). Many authors postulate possible reasons for the development of anorexia in the cancer patient. Shaw (15) mentions physical symptoms, such as nausea, vomiting, constipation, mucositis, dry mouth, oral candida, taste changes, and pain. Daly et al (?) mention altered taste perceptions from deficiencies in zinc and other trace elements;
specific metabolic processes that affect nutrient intake; local tumor effects, such as when the tumor arises from or impinges on the alimentary tract causing a mechanical obstruction; and psychological factors. Holroyde and Reichard (9) mention raised intracranial pressure; effects of cancer therapy; lesions of the lateral hypothalamus from the development of brain metastases; and increased brain concentrations of tryptophan and serotonin. Fearon and Carter (11) mention that some patients can be profoundly anorectic for no identifiable physical or psychological reason, and attribute the loss of appetite to some abnormal biochemical, metabolic, or hormonal mechanism yet to be defined. These authors also suggest that studies which show markedly decreased food intakes and severe wasting in patients with cancer cachexia have failed to show that anorexia is causing the cachexia or vice versa. Donoghue et al (16) mention early satiety from the sustained stimulation of receptors in the gastrointestinal (GI) tract; release of tumor by-products; difficulty in swallowing; fatigue; infection; the stress response; and changes in usual lifestyle pattern as being factors which cause appetite loss in the cancer patient.

**Alterations in Protein Metabolism**

In the normal, healthy adult, proteins are continuously synthesized and degraded so that the body's protein needs can be met under changing circumstances. This process is called turnover, and assures that skeletal and visceral protein, needed for body function, is maintained to allow survival. During starvation, the body decreases muscle breakdown to maintain the functional body protein, but this ability is lost in the cancer patient who
cannot undergo metabolic adaptation to decreased food intake (17-20). The result is marked depletion of protein mass, leading to clinical signs of skeletal muscle atrophy and myopathy, visceral organ atrophy, and hypoalbuminemia.

This protein wasting results from complex changes in nitrogen metabolism involving alterations in whole-body protein turnover, muscle protein synthesis and catabolism, liver protein metabolism, and plasma amino acid levels (12,18). Loss of protein stores may result in death once a critical mass has been reduced (12,13).

Relatively few studies have measured protein metabolism in humans with cancer, and results for existing studies vary. Lundholm et al (21) studied samples of rectus abdominus muscle from 43 cancer patients and 55 controls. They found that the degradation rate of proteins was increased in the muscle of the cancer patients. However, later findings by this group (22) imply that net loss of protein is related to decreased synthesis rather than to increased breakdown of muscle protein. In any case, it is estimated that nitrogen balance is negative in 30 - 100% of patients with progressive malignancy.

Cohn et al (23) studied changes in body composition in 37 patients with various types of cancer over a six-month period. Patients with solid tumors who had lost over 10% of their body weight (n=6) appeared to have lost body fat and water, and to a minor extent, body protein. Moley et al (24) estimated body cell mass (BCM) in 104 cancer patients, 233 normal controls, and 18 patients with anorexia nervosa. The patients with anorexia nervosa experienced marked weight loss (30.5%) and had significant depletion of absolute BCM, but exhibited the preferential utilization of body fat and the relative sparing of BCM. The cancer patients also had significant weight loss (12.7%
for females and 13.9% for males), but BCM was depleted to the same extent as body fat.

**Alterations in Fat Metabolism**

Alterations in lipid metabolism in cancer patients include changes in body composition and increased lipid mobilization (25,26). The net results are hyperlipidemia and decreased total body fat (17,27). Costa et al (28) conducted studies on the composition of human muscle samples from patients with various tumors and from patients with a variety of acute and chronic surgical conditions. In cancer patients, the average muscle fat content was approximately one half that of the controls. In another study, Warnold et al (29) found that in a group of untreated malnourished cancer patients, the loss of fat was the most pronounced alteration in body composition.

In contrast, Cohn et al (23) reported that the loss of body weight by patients with solid tumors consisted primarily of the loss of muscle mass with relatively less loss of body fat. They also observed that functional visceral proteins were spared to a considerable extent. However, most authors believe that lipid depletion is proportionally greater than protein loss and accounts for most of the weight loss seen in cancer patients (17,30). Lundholm (31) believes that the conflicting results found in the two previous studies may be due to the investigation of two truly different study populations.

According to McAndrew (30), there is evidence that cancer patients have lost the normal homeostatic responses to decreased energy intake or starvation that allow a decrease in oxygen consumption and protein sparing. Daly et al (7) and Heber et al (32) state that cancer patients
exhibit both increased lipolysis and increased oxidation of fatty acids. The byproducts of lipolysis, glycerol and fatty acids, serve as substrates for gluconeogenesis and energy production during periods of nutrient deprivation. Waterhouse (33) found that fatty acids are the major substrates in patients with progressive malignant disease. Shaw and Wolfe (34) used stable isotopes to study fatty acid and glycerol kinetics in weight-losing patients with gastrointestinal cancer. They demonstrated that cancer patients have increased rates of glycerol and free fatty acid turnover when compared to normals or cancer patients without weight loss. Glucose infusion in weight-losing cancer patients failed to suppress lipolysis, and these patients were unable to oxidize endogenous free fatty acids or intravenously administered lipid at a normal rate.

Elevated basal lipolysis has occasionally been seen early in tumor growth, suggesting the presence of a tumor-associated factor responsible for this increase in lipid mobilization (30). In her review article, McAndrew (30) discusses several possible mechanisms for the altered lipid metabolism seen in cancer. Metabolic substrates may be remodeled and directed away from fuel-efficient into energy-requiring pathways. An increased energy expenditure may occur as a result of the energy costs of tumor synthesis, an uncoupling of oxidative phosphorylation, or energy-requiring futile cycling. An overall depletion of lipid may be the final outcome of the inhibition of lipid deposition. Tumor necrosis factor/cachectin has recently been found to suppress the activity and synthesis of several key lipogenic enzymes, including lipoprotein lipase. Abnormalities in insulin secretion or sensitivity may be involved in the decrease of fat storage in
malignancy. Insulin also exerts an antilipolytic effect by its antagonism of hormone-sensitive lipase.

**Alterations in Carbohydrate Metabolism**

Review articles by Chlebowski and Heber (35) and Daly et al (7) mention a number of studies which indicate the presence of abnormal carbohydrate metabolism in cancer patients. One of the earliest metabolic abnormalities described in cancer patients was glucose intolerance (36); recent research has confirmed this observation (37-39). Although cancer patients have normal levels of circulating insulin and glucose, they have impaired insulin sensitivity (7). In some studies, the glucose intolerance seen in cancer patients is associated with a marked resistance to administered insulin (40,41). In other studies, glucose intolerance is documented by hyperglycemia and delayed clearance of blood glucose in cancer patients after oral or intravenous glucose administration (41-43). Glucose intolerance is, in part, due to decreased tissue sensitivity to insulin, but may also involve an attenuated insulin secretion to exogenous glucose (39,41). Lundholm et al (44,45) documented decreased glucose disposal and altered insulin kinetics in peripheral tissues in patients with cancer, and these authors suggest that there may be decreased pancreatic beta cell receptor sensitivity in cancer patients, leading to inadequate insulin release in response to glucose loading. These abnormalities in peripheral tissue glucose metabolism suggest a diabetic-like state, contributing to tissue wasting in the cancer patient (12).

In their review article, Kern and Norton (12) mention studies which may indicate a diabetic-like state of
elevated glucose production in the liver of the tumor-bearing host. In one such study, Shaw and Wolfe (46) have shown increased basal hepatic glucose production in patients with advanced gastrointestinal malignancies, and results demonstrated a relationship between rate of endogenous glucose production and tumor burden. Patients with early GI cancers had lower glucose production rates than patients with advanced GI cancers, who failed to suppress endogenous glucose production, consistent with a diabetic-like state.

Kern and Norton (12) mention that the cause of elevated hepatic gluconeogenesis in cancer patients is unclear. Increased amounts of gluconeogenic precursors released from the periphery and presented to the liver for conversion to glucose is one possible explanation. Clinical studies have documented increased gluconeogenesis from several substrates, including lactate (47), alanine (48), and glycerol (49). Presumably, the peripheral release of these substrates "drives" the liver to produce increased amounts of glucose. According to Kern and Norton (12), this elevation in hepatic glucose production by recycling of substrates is an energy-requiring process which wastes the cancer patient's energy. This increase in glucose production differs from the decrease in glucose turnover observed in cancer-free subjects experiencing weight loss due to starvation alone (42).

Alterations in Energy Expenditure

The role of energy expenditure in the development of cachexia and weight loss is an area of much debate. Studies have provided conflicting evidence with some showing increased energy expenditure, and others showing it
to be normal (15). Such discrepancies may be due to
differences in investigative approaches with regard to the
use of reference patients, and the degree of sensitivity,
stability, and reproducibility of the technology used to
measure energy expenditure (31).

In their review article, Chlebowski and Heber (35)
mention a study by Eden et al (50) of the potential energy
consequences of increased glucose turnover in weight-losing
cancer patients. Eden's group calculated that this change
in metabolism led to a loss of 0.9 kg of body fat per
month, or an increase in energy expenditure of 250 - 300
kcal per day. Chlebowski and Heber mention that increases
in energy expenditure of a similar magnitude have been
observed in a variety of cancer patient populations in at
least six other studies. These authors emphasize that
although this elevation is moderate, over the long term,
when combined with a reduced energy intake, significant
weight loss may result.

In another review article, Daly et al (7) mention
studies showing conflicting results about energy
expenditure. Young (51) reviewed a number of clinical
studies and concluded that resting metabolism was not
consistently elevated in all cancer patients, although
increased energy expenditure was noted in leukemia and
lymphoma patients. Shike et al (52) found that basal
energy expenditure was elevated in patients with small cell
carcinoma. In those who responded to chemotherapy, there
was a significant decrease in basal energy expenditure
while nonresponding patients showed no change. Knox et al
(53) measured energy expenditure, and found that only 41%
of cancer patients had a normal resting energy expenditure,
33% showed a decrease, and 26% showed an increase. Also,
Heber et al (43,54) found no clear evidence of
hypermetabolism in non cachetic lung cancer patients. However, they stated that since malnourished patients normally decrease basal metabolic rate as an adaptation to starvation, even normal predicted metabolic rates are inappropriately elevated in malnourished cancer patients. Shaw et al (55) argued that the alteration in metabolic rate depends on the type of tumor.

To date, it is unclear whether the weight loss seen in cancer patients is due primarily to reduced food intake, increased energy expenditure, or a combination of both (9,11). Kern and Norton (12) emphasize that the important point of these studies is that food intake fails to adjust to changes in the metabolic rate. Even a mild increase in metabolic rate must be met by an equivalent increase in caloric intake, or persistent weight loss will ensue.

Nausea, Vomiting, and Retching

Nausea, vomiting, and retching are well-recognized symptoms in the cancer patient. These symptoms may occur as manifestations of the underlying malignancy; as side effects from medications; or as a result of cancer therapies, especially chemotherapy (56-58).

According to Reuben and Mor (56), little is known about nausea and vomiting in cancer patients who are not receiving antineoplastic agents, or who are terminally ill. Using data from the National Hospice Study, these authors investigated 578 terminal patients with a variety of cancers who were cared for in conventional care settings, hospice beds within healthcare institutions, and at home in hospice care. Results showed that nausea or vomiting were present at some point within the last two months of life in 62% of patients with terminal cancer. Reported symptom

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severity remained relatively constant between initial and later follow-up interviews with patients. During the last six weeks of life, 21% of 578 patients reported nausea or vomiting at all assessments; 47% reported nausea or vomiting at least once or twice; and 32% never reported nausea or vomiting. Patients with stomach cancer, leukemia, breast cancer, and pancreatic cancer reported nausea and vomiting at rates at least 10% above the average. Women reported higher rates of nausea or vomiting, at 67%, compared to 56% for men. Also, patients younger than 65 years of age reported higher rates of nausea and vomiting at 67.7% than older patients at 59.2%. Of the patients who reported nausea and who were given a prescription, 72% consumed the antiemetic.

Guyton (59) defines nausea as a subjective experience, specifically the conscious recognition of the need or desire to vomit. Distress is usually noted in the throat and stomach. Nausea can be described as wavelike, and may be accompanied by tachycardia, increased salivation, and swallowing. Rhodes (57) explains how patients have great difficulty verbally describing the unpleasant sensation of nausea, which may be called a vague unpleasantness located in the region of the throat, the upper gastric region, or the abdomen. Nausea without some degree of anorexia is unusual, so these two symptoms may be confused when, in fact, anorexia may be a result of nausea.

Retching is described as the spasmodic movement of the abdominal muscles and diaphragm controlled by the respiratory center in the brainstem. Retching may occur in the absence of vomiting. Vomiting is the oral expulsion of gastric contents as a result of positive changes in the intrathoracic pressure. As the stomach contents become trapped between the forceful contractions of the muscles of
the abdomen and diaphragm, intragastric pressure builds, thus opening esophageal sphincters and initiating the act of vomiting (59).

In her review article, Hogan (58) mentions that nausea, vomiting, and retching are often described together, but are three separate problems. She also emphasizes that each individual has his or her own threshold for both nausea and vomiting, which partially accounts for the wide variations in symptoms seen among patients receiving the same cancer therapy.

The function of the emetic center in producing nausea, vomiting, and retching is a complicated subject, and will not be reviewed here.

According to Hogan (58), several conditions may be the primary cause of cancer-related nausea and vomiting, even if the patient has received chemotherapy or radiation therapy. These conditions include pain; constipation; liver dysfunction; renal dysfunction; and metabolic dysfunction, such as hyponatremia, hypokalemia, and hypercalcemia. Rhodes (57) mentions anxiety as a symptom often associated with nausea and vomiting, citing studies which correlated post-therapy state anxiety with post-therapy nausea and vomiting. She also mentions that fatigue is related to nausea, vomiting, and retching, although the relationship is not clearly understood.

Reuben and Mor (56) mention how nausea and vomiting in cancer patients may be due to fluid and electrolyte imbalances, including water intoxication or adrenocortical insufficiency; bowel obstruction; central nervous system or meningeal metastases; hepatic metastases; uremia; and psychogenic factors. They suggest that all of these causes, especially the disease complications, are likely to occur in terminal cancer patients. Worcester et al (3)

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mention other causes of vomiting in terminal illness, including three causes associated with tumor growth: hypercalcemia from extensive bone metastases; raised intracranial pressure from cerebral tumors; and intestinal obstruction. They also emphasize how anorexia, nausea, and vomiting may cause constipation by decreasing food and fluid intake, and how constipation may influence the development of anorexia, nausea, and vomiting by increasing sensations of fullness and nausea.

According to Hogan (58), successful management of cancer-related nausea and vomiting, regardless of etiology, is dependent upon an understanding of the pathophysiology of the symptoms, an appreciation of the efficacy and limitations of pharmacologic interventions, and the use of behavioral techniques. She emphasizes that uncontrolled emesis results in physical and psychological problems. Individuals undergoing cancer treatment and experiencing nausea and vomiting come to dread therapy, and may miss or delay scheduled treatments. Severe vomiting or retching may tear the esophagus. Uncontrolled nausea and vomiting may result in hyponatremia, hypokalemia, and metabolic alkalosis. Taste aversions, uncontrolled nausea and vomiting, and poor nutrition become so interrelated, they may become difficult to separate and control. Additionally, the patient and his significant others may become so overwhelmed and focused on these symptoms that the symptoms become the pivotal point around which the family functions and communication occurs.

**Constipation**

The term constipation has many different meanings, and may include the passage of hard, dry stools that cause
straining or painful defecation; an acute onset of absolute absence of stool; or a decrease in the frequency of stools. Stool frequency norms vary with each individual, and may range from three a day to once every three days, so "normal" must be measured by the patient's usual pattern (3).

One classification of constipation is primary or simple constipation, which is related to dietary or activity patterns. Primary or simple constipation may be characterized by hard stools, stools produced less frequently than usual, straining at stools, feelings of rectal pressure, or liquid stool leaking around a palpable impaction (60).

Constipation can also be classified as secondary, due to disease processes such as partial or complete bowel blockage, nerve damage, or inflammation of the bowel. Thin, pencil-like stools and painful defecation are characteristics of diverticular disease, hemorrhoids, or rectal cancer. With bowel obstruction, symptoms include rushes of loud, high-pitched or absent bowel tones, cramping pain, vomiting of intestinal contents, or abdominal distention (3).

Constipation can also be iatrogenic, resulting from the use of medications which have side effects of slowing bowel motility. The narcotics used in cancer pain management are often constipating (3).

Donoghue et al (61) mention other causes of constipation in the cancer patient. These include the presence of a tumor in the gastrointestinal tract, depression, anorexia, immobility, dehydration, and chemotherapy administration. They emphasize that constipation can potentially interfere with a patient's ability to maintain an adequate nutritional intake. When
the motility of the GI tract is decreased, the patient experiences a loss of appetite, which can be further aggravated by symptoms such as abdominal cramping, bloating, and headaches. Constipation may also lead to the development of diarrhea in some patients. When constipation has progressed to the point of impaction, explosive diarrhea may occur around the hard, dry stool.

Diarrhea

There are many possible causes of diarrhea in the cancer patient. Margie and Bloch (62) mention several, which include: some drugs; radiation or chemotherapy directed at the abdomen and/or chest; sensitivities to certain foods; surgical removal of part of the gastrointestinal tract; infections, especially of the intestinal tract; and other treatment modalities. Donoghue et al (61) expand upon some of these causes.

The cells of the gastrointestinal mucosa have a rapid mitotic rate and are susceptible to the toxic effects of chemotherapy and radiation therapy. When these treatment methods interrupt cell replication, the number of epithelial cells of the mucosa decreases, causing denuding of the intestinal villi, inflammation, edema, and over-production of mucus in the lower GI tract. This stimulates intestinal motility causing an increase in the transit time of the intestinal contents, resulting in diarrhea. Patients who have had surgery of the stomach and small bowel frequently develop diarrhea due to dumping and malabsorptive syndromes (61).

When intestinal motility is altered, diarrhea can result. Increased motility causes rapid transit time as previously mentioned. Decreased motility also causes
diarrhea by increasing the bacterial growth within the intestines, causing a decreased reabsorption of water from the colon (61).

Prolonged, severe diarrhea can produce loss of essential fluids and electrolytes. Chronic diarrhea can cause nutritional deficiencies since the rapid passage of food through the GI tract does not allow sufficient time for absorption and utilization of nutrients. Finally, diarrhea is an uncomfortable, distressing, and embarrassing occurrence, causing the patient anxiety, which can further aggravate the status of the diarrhea (61,62).

Tumor Effects

Tumors can affect nutritional status by compromising the gastrointestinal tract through mechanical obstruction, impaired digestion, and impaired absorption (63,64). Tumors of the oral cavity fungate or erode the mucosa and hamper mastication, altering the type and quantity of nutrients that a patient can ingest. Tumors within or outside of the stomach may partially obstruct this organ, hindering gastric emptying and decreasing the quantity of nutrients ingested. Stomach lesions can also cause blood loss and pooling through hemorrhage, leading to abdominal distention, gastrointestinal stasis, or nausea (63).

Intrinsic and extrinsic neoplasms may obstruct the small intestine and colon, leading to nausea, vomiting, and abdominal distention. Also, malabsorption of nutrients can result in dehydration, electrolyte imbalance, and protein deficiency. Tumors in the pancreas, common bile duct, or duodenum can contribute to malabsorption if secretion of the pancreatic enzymes necessary for digestion and absorption of protein, fat, and carbohydrate are
insufficient. The liver is often a site for metastasis, and tumors can lead to hypoalbuminemia; problems with blood coagulation; and malabsorption of fat, fat soluble vitamins, especially vitamin K, and vitamin B12 (63).

Tumors can also have distant effects. Tumors have inefficient metabolism, and cancer patients may have a higher energy expenditure than patients without cancer (64). Also, many tumors excrete hormones and other humoral factors which can mediate cancer cachexia and anorexia (9,17).

**Taste Alterations**

Trant's (65) review summarizes the results of eleven studies of taste in cancer patients. Nine of the studies reported taste threshold abnormalities for one or more of the four taste sensations of sweet, sour, salt, and bitter. However, results among studies were inconsistent. Gormican (66) explains how studies of taste acuity changes in cancer patients are easy to perform but difficult to interpret. Type of tumor, presence of metastasis, type of therapy, and patient idiosyncrasies complicate the objectivity of interpretation. Nutrient deficiencies or imbalances, such as a zinc deficiency, may affect taste sensation. Donoghue et al (63) mention how food odors also influence taste sensations. Food odors pass upwardly in the nasopharynx and stimulate the olfactory system, which in turn stimulates the sensation of taste. Alterations in the sense of smell also occur as part of the cancer process.

Various treatment methods may cause taste changes (63). Radiation to the oral cavity may result in decreased saliva and decreased taste bud function. Surgery of the tongue will alter taste. Certain chemotherapy agents may
produce a metallic taste or may denude the mucous membranes of the oral cavity (stomatitis) resulting in loss of taste. Any oral infection which produces a coating of the taste buds may cause loss of taste. Tumor by-products produced as cancer cells divide, or released when cancer cells are destroyed by cancer treatment, may cause changes in the sense of taste. Donoghue et al (63) emphasize that taste changes not only diminish the pleasure of eating, but also decrease the amount of saliva and gastric secretions which help digestion. These authors also mention that taste sensation returns to normal as patients respond to treatment, suggesting that the problem is probably a chemical alteration rather than a change in physiology.

DeWys and Walters (67) studied 50 patients with different types of cancer and 23 controls with other diseases. A total of 25 cancer patients reported a general reduction in the pleasurable aspect of taste, and many preferred highly sweet or seasoned foods. Sixteen patients reported an aversion for meats, which correlated with a lowered urea recognition threshold. The authors suggest that this correlation might be related to a lowered bitter recognition threshold, which would give the cancer patient a bitter sensation when tasting the amino acids, polypeptides, and purines present in meat. The authors also found that the likelihood of having a taste abnormality increases with increasing extent of cancer, but not with the type of cancer. Also, patients with an abnormality of taste had an increased incidence of weight loss compared with patients with normal taste, even though many in the latter group had other causes of weight loss.
Effects of Cancer Treatment on Nutrition

Antineoplastic therapy invariably affects the host, either by mechanical and physiologic alterations due to surgery, or at the cellular level with chemotherapy or radiation therapy (68). These treatments may be given alone or in combination, depending on the type and location of the neoplasm being treated. Nutritional complications resulting from these treatments can be both acute and chronic (69).

Surgery is primary treatment for many cancers, especially of the gastrointestinal tract. As a result of surgery in any patient, including one with cancer, energy requirements are increased. A net catabolic state results from the mobilization of fat stores, skeletal muscle protein, and visceral protein to meet the increased demand for glucose. A positive nitrogen balance is achieved within a few days in the cancer patient who undergoes an uncomplicated surgery for a malignancy. However, longer-term effects depend on the site of the tumor, the extent of resection, and whether or not a vagotomy was performed (68).

McAnena and Daly (68) mention some major nutrition-related effects from surgery in the cancer patient. Resection of segments of the tongue or mandible hampers deglutition. Surgery on the tongue, palate, or pharynx may alter the swallowing sequence either temporarily or permanently. Following gastrectomy, a modest weight loss of less than 10% of preoperative weight is common, even in patients with benign disease. This is a result of rapid gastric emptying (70) and altered intestinal transit (71). Food intake may be impaired after gastric surgery by a decrease in the size of the gastric pouch, leading to early satiety (72). Radical gastrectomy may result in
deficiencies of iron, vitamin B12, other B vitamins, and vitamins A and D (68).

Malfunction of the small intestine can occur if sufficient bowel is resected. Unless patients have undergone resection of more than 75% of their small bowel, the ability of the remaining small bowel to increase its absorptive capacity prevents major clinical problems after resection. Also, patients who undergo a total colectomy may develop large fluid and electrolyte losses from profuse diarrhea, but these symptoms usually resolve as the remaining small bowel adapts (68).

Surgery of the pancreas can result in severe nutritional deficiencies if pancreatic enzymes are lost. Following total pancreatectomy, a patient will have diabetes mellitus (68,69), and will require exogenous insulin. Liver resection may result in short term nutritional problems until this organ regenerates (68).

Most chemotherapeutic agents, with the exception of hormones, inhibit one or more key steps in the cell cycle, specifically actions involving protein synthesis. Since chemotherapeutic drugs are provided systemically, both normal and neoplastic cells are affected. Cells that have a more rapid turnover rate, such as the epithelial cells of the gastrointestinal area, are more susceptible to drug effects (69). The extent of the effects depends on the total drug dose, duration of treatment, and individual susceptibility (73). Symptoms of gastrointestinal mucosal involvement include anorexia, nausea, vomiting, diarrhea, constipation, mucositis, and stomatitis, any of which can severely limit food intake (69).

For the treatment of many tumor types, multiple chemotherapeutic agents are prescribed. The acute toxic effects may begin promptly with the infusion of the drugs,
and last for two to five days following delivery (69).

Cancer chemotherapeutic agents almost invariably are associated with nausea and vomiting to some degree (68). Donoghue et al (74) mention four reasons why nausea and vomiting occur in response to these substances: (1) a conditioned emotional response due to previous experience with nausea or vomiting; (2) gastric irritation from oral chemotherapy agents; (3) gastrointestinal toxicity caused by the destruction of normal cells of the GI tract; and (4) the release into the bloodstream of the toxic products of cellular breakdown. Medical complications of vomiting depend upon its severity and duration, and can include esophageal tears, bone fractures, malnutrition, and major fluid and electrolyte derangements (75). In some patients, nausea and vomiting may not only lead to noncompliance with treatment regimens, but often impose mental and physical suffering that diminishes quality of life (75). But overall, the gastrointestinal side effects of chemotherapy are temporary (68, 69).

Other side effects of chemotherapy which are not related to the GI tract may include neurotoxicity, with depression, parasthesia, weakness, or jaw pain; impaired renal or hepatic function; taste changes; and leukopenia and anemia, leading to infections, fatigue, and anorexia (74). In addition, specific chemotherapeutic agents are associated with well-documented deficiencies or alterations in micronutrient metabolism: 5-fluorouracil with thiamin deficiency; cisplatinum with increased urinary excretion of magnesium; and methotrexate with competitive inhibition of folate (76).

Nutrition problems that result from radiation therapy are caused by direct radiation effects on normal and neoplastic tissues in the irradiated area. Curative doses
of radiation therapy are designed to irradiate cancerous tissue, but also alter the function of normal, surrounding tissues (69). Effects on the rapidly dividing mucosal cells of the gastrointestinal tract can significantly impact host nutrition status. Early symptoms include diarrhea, with or without gastrointestinal bleeding, nausea, vomiting, weight loss, mucositis, xerostomia, alterations in taste, and food aversion. Patients receiving whole body irradiation develop emesis almost immediately (68). Seven to 15 days later, an intestinal syndrome develops, which is characterized by diarrhea, often accompanied by intestinal bleeding (77). Later gastrointestinal complications can include stricture, fistula, bowel perforation, and malabsorption (78).

Any time radiation therapy involves the head and neck or the gastrointestinal tract, patients risk developing nutrition problems. Radiation of the central nervous system may result in anorexia, nausea, or vomiting when centers of the brain that regulate eating behavior are involved. The extent of symptoms from radiation therapy is dependent upon total dose administered, tumor location, duration of treatment, and total area irradiated (69).

The soft tissues of the mouth and pharynx are quite sensitive to radiation. When these areas are treated, inflammation and mucositis may occur after only five to seven days of therapy. The local irritation of the tissues continues during the course of treatment and for about a week following, or until tissues are healed. Symptoms include sore throat, diminished salivary secretion, and altered taste and smell. Generalized inflammation and attendant pain with swallowing can severely limit food intake in any form. The problem of dry mouth from diminished salivary secretion can also limit food intake.
Although the symptoms may be temporary during the course of treatment, patients frequently do not experience complete return of saliva production or normal taste sensation (69). The development of mandibular osteoradionecrosis is the most serious long-term complication of head and neck cancer (68).

Radiation therapy used to treat thoracic malignancies often results in esophagitis, which may lead to dysphagia, thus adversely affecting food intake (68). Radiation to the abdomen and pelvis frequently leads to irritation of the GI tract, resulting in acute symptoms of nausea and vomiting. Symptoms of malabsorption, including diarrhea, may begin within one week of therapy, and result from the acute insult of radiation to the normal absorptive surfaces of the small intestine (69). Chronic radiation injury to the absorptive surface of the intestine can lead to symptoms such as intermittent bowel obstruction, fibrosis, ulceration, perforation, and generalized malabsorption, all of which can occur as late as ten years following treatment (69).

The immunosuppressive effects of radiation therapy leave the patient very tired during the four to six weeks of treatment. Usual eating times may be interrupted by travel to and from the treatment center, and the patient returns home too exhausted to prepare food or eat (69).

Use of Medications to Control Symptoms

There are many drugs which can be prescribed for cancer patients to relieve the many different symptoms experienced as a result of the disease and its treatment modalities. This section will review some of the most common classes of drugs prescribed for cancer patients, and
some of their nutrition-related side effects.

The first major type of drug prescribed for cancer patients is the analgesic for pain. In advanced cancer, pain is primarily due to tumor involvement, chemotherapy, or a combination of the two. Other influencing factors are related to the patient's overall physical condition and frame of mind, and include fatigue, anxiety, fear, depression, and the presence of multiple chronic illnesses, especially in older adults. Medication is usually a necessary treatment for adequate pain relief, and the medications chosen vary according to the origin of the pain, e.g., bone, soft tissue, or muscle tension. In addition to the types of medications for pain, there are now a wide variety of administration methods, such as sublingual, oral, liquid, capsules, suppositories, subcutaneous, intravenous, implanted infusion pumps, and PCA (patient-controlled analgesia) (3).

Analgesics drugs are classified according to their chemical receptor and pharmacologic properties, their sites and mechanisms of analgesia, and the intensity of the pain for which they are generally used. Analgesics can be classified into several groups: (1) the nonopioid analgesics for mild-to-moderate pain, including acetaminophen, aspirin, and the nonsteroidal anti-inflammatory drugs (NSAIDs); (2) the weak opioid analgesics for mild-to-moderate pain, including codeine, oxycodone, and propoxyphene; (3) the strong opioid analgesics, including morphine and related opioids; and (4) the adjuvant analgesic drugs, used as coanalgesics in special types of pain, or used to counteract the adverse effects of the opioids (79).

Any of the above drugs can cause a patient to experience nutrition-related side effects. The NSAIDs can
cause gastric irritation and can be nephrotoxic. Other possible side effects are nausea, vomiting, salt and water retention, headache, somnolence, dizziness, tremors, confusion, insomnia, nervousness, muscle weakness, fatigue, and drowsiness (80,81). The steroids can cause increased appetite, gastric irritation, oral candidiasis, edema, agitation, and insomnia (80). General effects from narcotic drugs can include respiratory depression, sedation, nausea and vomiting, constipation, central nervous system hyperexcitability, dehydration, dry mouth, drowsiness, delayed digestion, and urinary retention (3,79,80,81).

Figure 2 lists common analgesics prescribed for cancer patients and their nutrition-related side effects (3).

Dyspnea is a common and distressing symptom experienced by cancer patients. In prolonged dyspnea, malnutrition often occurs due to the energy expended in breathing as well as the cancer pathology. The muscle wasting resulting from malnutrition then increases difficulty of breathing, creating a vicious cycle. Shortness of breath is increased during meal times because of the obstruction of the airway during swallowing (3).

Figure 3 lists drugs commonly used to treat dyspnea and some possible nutrition-related side effects (3).

The common symptoms of nausea and vomiting have been described previously, and antiemetics are often prescribed for the cancer patient. Figure 4 lists antiemetic drugs and their side effects which can affect food intake (3).

Constipation is a very common symptom experienced by the cancer patient. Laxatives, suppositories, and enemas are commonly used to relieve this condition. Figure 5 lists some laxatives which may cause nutritional complications (3).
<table>
<thead>
<tr>
<th>DRUG</th>
<th>SIDE-EFFECTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aspirin</td>
<td>chronic excessive use may cause gastric blood loss and prolonged bleeding</td>
</tr>
<tr>
<td>Acetaminophen</td>
<td>may cause liver damage</td>
</tr>
<tr>
<td>Ibuprofen</td>
<td>like aspirin</td>
</tr>
<tr>
<td>Naproxen</td>
<td>like aspirin</td>
</tr>
<tr>
<td>Prednisone</td>
<td>sodium and fluid retention, fatigue</td>
</tr>
<tr>
<td>Morphine</td>
<td>constipation, vomiting, bitter taste</td>
</tr>
<tr>
<td>Hydromorphone</td>
<td>like morphine</td>
</tr>
<tr>
<td>Methadone</td>
<td>sedation</td>
</tr>
<tr>
<td>Codeine</td>
<td>nausea, vomiting, dizziness, drowsiness, constipation</td>
</tr>
<tr>
<td>Oxycodone</td>
<td>like codeine</td>
</tr>
</tbody>
</table>

Figure 2: Commonly-prescribed analgesics and their nutrition-related side effects (3)
<table>
<thead>
<tr>
<th>DRUG</th>
<th>SIDE-EFFECTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theophylline</td>
<td>tremors, irritability,</td>
</tr>
<tr>
<td>Slophyllin</td>
<td>insomnia</td>
</tr>
<tr>
<td>Theo-dur</td>
<td></td>
</tr>
<tr>
<td>Isoproterenol</td>
<td>tremors, nervous</td>
</tr>
<tr>
<td></td>
<td>apprehension, palpitations</td>
</tr>
<tr>
<td>Prednisone</td>
<td>sodium and fluid retention</td>
</tr>
<tr>
<td>Codeine</td>
<td>nausea, vomiting,</td>
</tr>
<tr>
<td></td>
<td>dizziness, drowsiness,</td>
</tr>
<tr>
<td></td>
<td>constipation</td>
</tr>
<tr>
<td>Hydroxyzine</td>
<td>irritability</td>
</tr>
<tr>
<td>Atropine</td>
<td>excitability, increased heart rate</td>
</tr>
<tr>
<td></td>
<td>and blood pressure</td>
</tr>
</tbody>
</table>

Figure 3: Drugs commonly prescribed to treat dyspnea and their nutrition-related side effects (3)
<table>
<thead>
<tr>
<th>DRUG</th>
<th>SIDE-EFFECTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticholinergics</td>
<td>sedation</td>
</tr>
<tr>
<td>Antihistamines</td>
<td>drowsiness</td>
</tr>
<tr>
<td>Barbiturates</td>
<td>respiration depression, somnolence</td>
</tr>
<tr>
<td>Benzodiazepines</td>
<td>sedation</td>
</tr>
<tr>
<td>Benzoquinolizines</td>
<td>sedation</td>
</tr>
<tr>
<td>Butyrophenones</td>
<td>hypertension, sedation, somnolence, agitation, restlessness</td>
</tr>
<tr>
<td>Cannabinoids</td>
<td>somnolence, hypertension</td>
</tr>
<tr>
<td>Phenothiazines</td>
<td>dry mouth, constipation, nasal stuffiness, faintness, sedation</td>
</tr>
<tr>
<td>Steroids</td>
<td>lethargy, weakness</td>
</tr>
<tr>
<td>Substituted Benzamides</td>
<td>anxiety, restlessness</td>
</tr>
</tbody>
</table>

Figure 4: Commonly prescribed antiemetics and their nutrition-related side effects (3)
<table>
<thead>
<tr>
<th>DRUG</th>
<th>SIDE-EFFECTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bulk products</td>
<td>require adequate food and fluid intake or the bowel can become occluded</td>
</tr>
<tr>
<td>Saline cathartics</td>
<td>do not encourage normal bowel movements; may cause discomfort</td>
</tr>
<tr>
<td>Emollients Lubricants</td>
<td>do not increase intestinal motility; are rarely adequate to provide regular defecation</td>
</tr>
<tr>
<td>Stimulant cathartics</td>
<td>are habit-forming</td>
</tr>
<tr>
<td>Suppositories</td>
<td>can cause cramping or rectal trauma with bleeding and/or infection</td>
</tr>
</tbody>
</table>

Figure 5: Types of laxatives and their nutrition-related side effects (3)
Psychosocial Factors Affecting Food Intake

Tumor growth, oncologic surgery, radiotherapy, chemotherapy, and enteral or parenteral nutrition have a psychologic as well as a physiologic impact on food intake in cancer patients (82). The presence of cancer and its ramifications can cause an emotional reaction in the patient, including depression, confusion, anxiety, fear, anger, grief, insomnia, pain, discouragement, and a general lack of well-being, and can result in anorexia (4,74,83). Hospitalization can negatively impact nutritional status in many ways. Meal time is usually an isolated experience with little or no interpersonal interaction; food service is impersonal; and the type and quality of food may be significantly different from what the patient is accustomed to (74,83).

Padilla (82) divides the psychologic aspects of nutrition and cancer into four types of responses: behavioral, emotional, perceptual, and attitudinal. She mentions three common behavioral consequences of cancer and its treatment: learned food aversions that affect ingestion and retention of food; changes in food preferences and selections; and anticipatory nausea and vomiting prior to the administration of chemotherapy or radiation therapy. Emotional responses to cancer and its treatment are well-documented, and were mentioned previously. For example, depression was found to be present in 25% of cancer patients (84). Perceptions that influence food intake include the presence of food, meal times, assessments of appropriate intake, availability of further food, palatability of food, and thoughts and beliefs about food. Finally, people have attitudes toward food, and may view it as an expression of love, a status symbol, as having religious significance, or as poison or taboo. Padilla
(82) emphasizes that the impact of cancer on attitudes toward food needs further study.

Weber and Dalton (85) found three factors which were central to understanding food habits and changes in food habits for three AIDS patients they studied for a six-month period. These factors were social isolation, illness symptoms, and control or lack of control. These authors determined that social isolation of the patients was the most important condition related to food intake, leading to difficulties in shopping, cooking, and feeding tasks. Lack of control over food intake was precipitated by social isolation and debilitating symptoms. The three patients lost control over the nature of the meals presented to them because of lack of funds, and eating at feeding centers, and their food intake decreased. Menashian et al (86) also mention the importance of control over food intake for cancer patients. They found that when a cancer patient learns to manipulate her diet during chemotherapy, she feels less helpless and has a new tool to use in attempting to manage side effects, such as nausea and vomiting.

Holden (87) describes the emotional and psychologic impact of anorexia on the terminally ill cancer patient and the family. To fourteen hospice patients and their primary caregivers, she administered a semi-structured interview to determine the subject's views and responses to the patient's loss of appetite. She found that loss of appetite was a source of anxiety and conflict within the family, and that the amount of food and fluid the patient took in was used to assess the patient's overall condition. The caregiver often becomes obsessed with serving something the patient will eat, and food can become a battleground for patients who have lost control in so many other areas of their lives. Caregivers frequently reported anorexia to
be of greater concern than other problems, while patients cited symptoms such as pain, breathing difficulties, weakness, fear of death, and fear of being alone as more important. The patients also indicated that family members should be less assertive, or should simply let them choose what and how much they wanted to eat. Holden (87) emphasized that family members may be better able to cope with anorexia if they know that it is a physiologically explainable and expected consequence of the disease over which the patient has little control.
REFERENCES


Chapter 4: The Role of Nutrition in the Cancer Patient

As described previously, cancer is often associated with a host of clinical symptoms and conditions which adversely affect food intake in the patient. Cancer treatment methods, use of medications to control symptoms, and psychologic and social factors also affect food intake. The cancer patient is often malnourished, and malnutrition has been found to be associated with a poor prognosis (1,2).

It would seem logical that nutrition intervention to improve nutrition status would improve prognosis also. This chapter will review if and how nutrition benefits the cancer patient; what cancer patients actually eat; what some authors believe are the necessary nutrient requirements for cancer patients; and common suggestions given to increase oral food intake.

The Importance of Nutrition for the Cancer Patient

In 1932, Warren (3) proposed that malnutrition was a major cause of death in cancer. As a pathologist, he found cachexia to be the only autopsy finding associated with death in 22% of patients with advanced cancer. More recently, DeWys et al (2) found that for patients with most common solid tumors, a decrease in survival rate of from 30% to 50% was associated with even moderate degrees of weight loss, of less than 5% of body weight. It is generally accepted that malnutrition, cachexia, anorexia, and weight loss, all common conditions in cancer patients, directly impact on survival. However, the effectiveness of providing nutrition support to influence clinical outcome in cancer patients has not been established (4-7).
Many studies have been done to determine how providing nutrition to cancer patients affects malnutrition, tumor growth, survival, and response to cancer treatment modalities. However, results have often been inconclusive and contradictory.

In one early study, Terepka and Waterhouse (8) force fed a group of terminally ill cancer patients, and found no benefit in terms of quality or quantity of life. Lipman (9) mentions how other early studies seemed to indicate that parenteral nutrition might improve nutrition status, tolerance to cancer therapies, remission, and survival. However, these studies were uncontrolled. In one study from 1976 by Copeland et al (10), the authors administered intravenous hyperalimentation (IVH) to 406 cancer patients as an adjunct to treatment. They found that use of IVH as an adjunct to chemotherapy in 175 patients resulted in an average weight gain of 5.6 lbs, and tumor response (more than 50% reduction of measurable tumor volume) was obtained in 27.8% of patients. Responding patients survived an average time of 8.2 months, whereas the non-responding patients survived only 1.9 months. Of 100 surgical patients, those who received IVH both pre- and postoperatively had fewer surgical complications, and no mortality. Finally, 95% of the radiation therapy patients (n = 39) completed their planned course of treatment, and 54% responded with a greater than 50% reduction in tumor volume.

In contrast, a more recent study by Heber et al (6) provided a continuous enteral infusion for 28 days to six patients with head and neck cancer without metastatic disease. Patients received a weight-maintaining regimen for seven days and an anabolic regimen for 19 days. Nitrogen balance, glucose production rates, and other
clinical characteristics were determined for all subjects. The patients failed to gain weight despite the administration of apparently adequate kilocalories. The authors concluded that simple kilocalorie administration by either the parenteral or enteral route is unlikely to reverse or delay the progress of malnutrition in patients with active cancer because of the presence of metabolic abnormalities.

Numerous animal studies clearly demonstrate that oral and parenteral nutrition can significantly stimulate tumor cell proliferation and distant metastasis. Torosian (7) reviewed research and clinical work on the effect of nutrients on tumorigenesis, primary tumor growth, and metastasis. In reviewing four human studies, he concluded that although cellular kinetic studies in humans have shown alterations following administration of Total Parenteral Nutrition (TPN), objective measures of tumor growth and tumor protein synthesis have not been altered by TPN. He concluded that the controversy of tumor stimulation by nutrition support remains, and more clinical investigation is needed.

Several review articles examine studies relating nutrition support with effects on cancer and its treatments. Koretz (11) reviewed eleven reports using parenteral nutrition (PN) as an adjunct to chemotherapy, four studies using PN in radiation therapy, and one using PN alone in terminal cancer patients. He noted that only in the study with terminal cancer patients was a statistically significant improved survival shown to be associated with using PN. In one study in colorectal cancer patients, those receiving PN showed a statistically significant reduction in survival. Koretz examined ten studies of objective tumor response in patients receiving
PN and undergoing chemotherapy, radiotherapy, or no therapy. Each study had an experimental group who received PN and a control group. None of these trials showed a statistically significant difference between the two treatment groups, except for one study involving leukemia patients. Koretz also examined the impact of PN on the side effects of various chemotherapeutic agents or radiation in 15 studies. After looking at the occurrences of gastrointestinal problems, hematologic toxicity, sepsis, and bleeding, Koretz concluded that no significant evidence has yet shown that PN had any positive benefits in patients receiving chemotherapy or radiotherapy for various types of malignancies.

Lipman (9) reviewed 18 reports of adjunctive PN in adults and five reports of adjunctive PN in children. In ten of the trials, weight gain was reported in patients receiving TPN, and in two trials, improvement in nitrogen balance was found. In one study, bone marrow transplant recipients receiving TPN were found to have a significantly increased length of survival. In another study, patients with limited-disease small cell lung cancer receiving TPN showed an increase in complete remission. Three studies revealed a decreased survival or shortened remission in patients receiving TPN. Seven trials demonstrated some benefit with respect to chemotherapy or radiotherapy toxicity in patients receiving TPN, while three studies reported poorer tolerance to therapy in patients receiving TPN. Lipman concluded that, other than weight maintenance or gain, improvement in nutrition status, when it does occur in cancer patients, has not translated into improvement of any outcome measure. The one exception was bone marrow transplant patients for whom early adjunctive therapy improved response and survival.
A series of randomized clinical trials was initiated to examine the use of TPN in patients with a variety of metastatic cancers. Recently, the American College of Physicians (12) published a position paper based on a meta-analysis of the results of these trials. Results showed that patients receiving TPN support plus chemotherapy survived only 81% as long as the patients who received only chemotherapy and no TPN. In terms of tumor response, patients receiving TPN were only 68% as likely to show a reduction in tumor size as were patients not receiving TPN with their chemotherapy. The patients receiving TPN were more than four times as likely to suffer an infectious complication as those who did not receive TPN. The conclusion of the position paper was that "parental nutrition support in patients with advanced cancer (is) associated with net harm" and "no condition could be defined in which such therapy was of benefit". Overall, many authors believe that aggressive nutrition therapy does not significantly influence the outcome of patients with advanced cancer (13-16).

Based on the literature and their own research, Bruera and MacDonald (13) published the following conclusions about the use of nutrition support in patients with cancer: (1) aggressive nutrition support does not prolong survival, increase tumor response, or decrease toxicity to cancer treatment modalities; (2) nutrition support has not been shown to have symptomatic benefits; and (3) the routine use of enteral and parenteral nutrition should be discouraged, except in very select cases.

Tchekmedyian et al (17) question the validity of using the impact on malignancy and survival time as the main outcome variables of clinical cancer treatment trials, including nutrition intervention studies. It is their view
that such trials should include variables that are meaningful to the patients of the tested intervention. These authors suggest that endpoints of nutrition trials in patients with advanced cancer should also include: (1) being free of such common problems associated with cancer as pain, nausea, anorexia, and weakness; (2) the functional status of the patient including physical fitness and performance status, and psychological and social functioning; (3) patient morbidity, including side effects of the nutrition intervention, time spent in the hospital, and complications related to cancer treatment; and (4) cost of therapy.

Food Intake of Cancer Patients

Little research has been published about what cancer patients, especially, the terminally ill, actually eat. The majority of the articles on this subject deal with food preferences and aversions. Few authors address caloric and nutrient intakes, and only four articles about terminally ill patients were found.

The study of food preferences and aversions in cancer patients is often experimental, involving sensory evaluation of taste and olfactory abilities, and theorizing about the physiologic mechanisms involved. Such articles will not be reviewed for this dissertation. Rather, this review will concentrate on specific food preferences and aversions which have been observed in or reported by cancer patients, and on actual foods eaten or avoided.

Gormican (18,19) completed an extensive survey of cancer care institutions to determine, evaluate, and report on successful diet practices of dietitians and other health care personnel in feeding anorectic cancer patients. The
survey focused on oral food intake of both adult and pediatric cancer patients with tumors of different types and locations. Part of the survey asked respondents about their observations of food preferences of adult inpatients and outpatients following surgery, radiotherapy, and chemotherapy.

According to the health care personnel surveyed, adult post-surgical cancer patients most frequently preferred the following liquids: nectars, apple and grape juices, Seven-Up, ginger ale, Coke, popsicles, jello, tea, and broth. Dairy products, especially custard, ice cream, and milkshakes, were well-liked. The most frequently preferred non-liquid foods were sandwiches, canned fruit, fresh fruit, soups, cottage cheese, cheese and crackers, eggs, mashed potatoes, peanut butter and crackers, and salad plates. Cold foods were most preferred.

Adult cancer patients receiving radiotherapy preferred a wide variety of foods, depending upon what foods could be tolerated while enduring symptoms such as nausea, diarrhea, or constipation. Liquids which were well-accepted by radiotherapy patients included: apple and grape juices, nectars, Seven-Up, ginger ale, jello, popsicles, tea, broth, milk, and dairy products. The most frequently preferred nonliquid foods were: soups, sandwiches, canned fruit, puddings and custards, fresh fruit, cheese and crackers, eggs, cottage cheese, and hard candy. Again, cold foods were strongly preferred. Patients showed strong aversion to meats, especially beef, pork, lamb, veal, poultry, and fish.

Adult cancer patients undergoing chemotherapy, like the radiotherapy patients, preferred various foods according to the side effects present such as stomatitis, nausea, diarrhea, and constipation. Again, apple and grape
juices, nectars, and Seven-Up were popular beverages, as were ice cream, milkshakes, sherbert, and custard. Most-preferred nonliquid foods were canned fruits, sandwiches, cheese and crackers, soups, fresh fruit, puddings, and cottage cheese. Chemotherapy patients exhibited the same aversions for meat as radiotherapy patients. Generally, adults liked blandly flavored foods during radiotherapy, and highly seasoned foods during chemotherapy.

Several authors researched food preferences and aversions directly with cancer patients. Vickers et al (20) studied 111 patients with a variety of cancers and 205 healthy controls. The patients had biopsy-proven cancer which had metastasized, and were being treated, or were going to be treated, with chemotherapy. All subjects completed a questionnaire of likes and dislikes and any recent changes in smell or taste for 39 different foods sorted into 12 classes. The foods rated least pleasant by cancer patients were red meats; high-protein foods; meat, fish, and poultry; cereal products; sweet foods; and salty foods. Forty-two percent of patients reported a taste change for hot coffee, which was the second largest taste change reported for any of the food items, except for roast beef (44%).

This aversion for meat was also found by DeWys and Walters (21) who studied 50 patients with metastatic cancer and 23 controls. Sixteen patients reported an aversion for meats, especially red meats. Some were able to eat poultry and fish while others avoided all meats, but could tolerate eggs, cottage cheese, and other cheeses. Ten patients reported a bitter taste on ingesting coffee or chocolate. These authors also performed objective tests in their subjects, measuring recognition thresholds for taste for NaCl, sucrose, HCl, and urea. The authors suggest that the
symptom of meat aversion may be correlated with a lowered taste threshold for bitter (urea), and that this correlation may be related to the amino acid, polypeptide, and purine content in the meat. A number of amino acids, polypeptides, and purines in pure form are bitter in taste, and a patient with a lowered bitter threshold may experience a bitter sensation from, and thus develop an aversion to, meat products.

Bernstein (22), who has researched food aversions extensively in both humans and animals, notes that while documenting chemotherapy-induced food aversions in cancer patients as well as food aversions that spontaneously arose in healthy college students, a substantial proportion of aversions appeared to be directed at foods that were protein sources, such as fish, eggs, and meat.

One group of researchers studied food aversions in cancer patients during the course of radiation therapy (23). Forty-nine patients with different types of cancer were interviewed immediately before their first course of radiotherapy and at 3, 5, 7, 14, 21, and 28 days after, as well as 2, 4, and 6 months following initiation of therapy. A 24-hour diet record was taken at the first meeting and patients rated the acceptability of all ingested items on a nine-point scale ranging from "I would eat this every opportunity I had" to "I would eat this only if I were forced to". The patients kept a record of all items ingested for the following 24 hours, again rating the acceptability of all items. All items recorded on the two diet records were rerated at each interview with the same scale.

By the end of the study period, 14 patients (29%) reported food sensitivities, primarily to acidic foods which irritated oral lesions. Twenty-seven patients (55%)
had pretreatment food aversions to vegetables, especially cruciferous varieties (42%); meats, especially red meat (27%); and to lesser degrees to sweets, fats, dairy products, caffeinated beverages, alcohol, and spicy foods. In the total sample, 29 patients (59%) formed a new aversion subsequent to the initiation of treatment. Foods which most commonly became aversive to the cancer patients were grain products, including breads, cereals, crackers, spaghetti, and waffles; meats, especially red meat; sweets, especially chocolate flavored items; and vegetables, especially potatoes and tomatoes. Ice cream and cheese were the only dairy products to become aversive.

A number of authors have reported actual energy or nutrient intakes of cancer patients. An early study was done by Theologides et al (24) who studied 39 cancer patients admitted to the hospital whose original diagnosis was made within three years prior to admission. During the previous three years and during hospitalization, the patient had to have been on a normal diet. Patients exhibited no edema, diarrhea, malabsorption, gastrointestinal obstruction, or obvious mental or emotional depression causing anorexia. Patients had various types of cancer but had received no chemotherapy or radiotherapy. Dietary recalls were taken to determine average daily dietary intake from six months to one year prior to the original diagnosis of cancer; at the time of the diagnosis; immediately prior to the admission; and 3 to 5 days prior to chemotherapy or radiotherapy.

Prior to diagnosis, the energy intake of all 39 patients was comparable to controls and met or exceeded recommended limits. Eighteen patients (Group A) had exhibited weight loss of more than 10% of their usual body weight between the time prior to diagnosis and immediately
prior to admission to the study. These 18 patients showed decreased energy intakes from 301 to 2,241 kcal. Of the 21 patients (Group B) without weight loss prior to the study, only four had decreased energy intakes ranging from 453 to 1,351 kcal. After admission to the hospital, six patients in Group A increased their energy intake by more than 300 kcal, six decreased it, and the remaining six had no change. In Group B, five had an increase, six a decrease, and the rest maintained the same energy intake. The decrease in energy intake in the majority of patients in both groups resulted from a decrease in all three major nutrients, carbohydrate, fat, and protein. Interestingly, these authors found no significant changes or particular trends in food cravings and intolerances, except for an increase in coffee consumption after the diagnosis of cancer in a few patients.

Costa et al (25) studied food consumption in 199 cancer patients and 205 normal subjects. Patients had a variety of cancers, were free from brain metastases or intestinal obstructions, had not received radiotherapy to the head and neck, and were not being irradiated. Most patients were receiving chemotherapy. Dietary intakes were estimated by 24-hour recall and three-day diary records in both groups, and the results were reported from the 24-hour recalls.

The male cancer patients (n = 76) ate significantly less than the healthy controls (1,894 vs 2,358 kcal/day). Female cancer patients (n = 129) maintained their food consumption near the level of their normal counterparts (1,556 vs 1,612 kcal/day).

Enig et al (26) investigated spontaneous changes in food intake before and twice during nonsurgical treatment
of 23 patients with small cell anaplastic carcinoma of the lung. The patients (21 female and 2 male) received radiotherapy for two weeks, followed by a course of chemotherapy, and another two weeks of radiotherapy. Food intake was recorded for four days before and after each treatment, and nutrient intake was calculated by computer program.

Before treatment, the average energy intake of the 23 patients corresponded to the requirements of healthy people with a low physical activity level, and the protein intake was greater than the recommended 0.8 g/kg of body weight. The energy intake dropped during the treatment period, but not significantly, and the protein intake remained unchanged. The mean energy intake (average of three measurements) was 137% of basal metabolic rate (9,100 KJ) and the mean protein intake was 0.94 g/kg body weight.

In another study, Enig et al (27) estimated food intake and nutrition status in 34 patients with different cancers and 25 healthy subjects. All subjects were asked about consumption frequency of various foodstuffs and drinks over the last two months. The size of portions was estimated in common household measures, and the average daily nutrient intake was calculated by computer program. Data analysis indicated that the patients' average intake of cheese, eggs, rye bread, and poultry was significantly reduced compared to controls. Reduction was most pronounced in patients who were in relapse with distant metastasis who showed significantly reduced intakes of fat products, fish, and sliced meat. The intakes of total energy, digestible carbohydrate, fat, alcohol, and protein in patients were not significantly different from the intakes in control subjects, but sugar intake was significantly greater in patients compared to controls.
The intakes of indigestible carbohydrate, vitamin B12, iron, and iodine were significantly decreased in patients compared to controls. Relapse patients showed the most pronounced changes in the intakes of these nutrients, and also showed significantly reduced intakes of vitamins D, E, B6, and zinc, sodium, and phosphorus compared to the controls.

Grosvenor et al (28) studied 254 adult patients with unresectable carcinoma and adequate hepatic and renal function. Some patients had prior surgery, chemotherapy, or radiotherapy, but all evaluations were done at least three weeks after any of these procedures. All subjects were inpatients at a medical research center. A 24-hour diet recall with food frequency and a weight history were taken, and patient symptoms which might affect weight loss were surveyed. Current energy intake expressed relative to "current" measured body weight (as kcal/kg current body weight/day) was not significantly different in groups with or without weight loss (31.4 ± 1.5 vs 30.5 ± 1.1 kcal/kg/d, respectively). Also, caloric intake at the time of study was similar in the prior chemotherapy and no prior chemotherapy groups. The symptoms most frequently identified in all patients were abdominal fullness (61%), taste changes (46%), constipation (41%), mouth dryness (41%), nausea (39%), and vomiting (27%). Multivariate analysis showed that these symptoms occurred more frequently in the group with weight loss. Also, decreases in B12 intake did not correlate with increased symptoms.

Grindel et al (29) studied 19 women with breast cancer and matched controls. The cancer patients had mastectomies or lumpectomies, and were receiving chemotherapy or both chemotherapy and radiotherapy following surgery. A longitudinal design with repeated measures was used to
assess the nutrition patterns of the subjects during their first six months on chemotherapy. Dietary preferences were measured using the Dietary Preferences Questionnaire which consists of 56 food items divided into eight sections. Energy intake and frequency of selection were calculated from a Three-Day Dietary Diary, and dietary eating patterns were assessed from the Dietary Frequency Questionnaire. Each subject completed five sets of questionnaires throughout the six months.

The cancer patients consumed a greater number of kilocalories over a three-day period than did the healthy women, and consumed more kilocalories within the breads/grains and the meat/fish categories. However, the cancer patients consumed more food servings from the white, bland protein items. Also, the cancer patients consumed a greater number of food servings than the controls.

At the onset of the study (Time 1), six subjects (31.6%) noted recent changes in taste, finding cakes, beef, chicken, and tea less appetizing. At Time 5, twelve subjects (63.2%) reported changes in the taste of beef, pork, chicken, ice cream, and cakes. Twelve of the cancer patients (63.2%) reported making alterations in their diet by eating more nutritious foods, avoiding red meat and animal fat, eating more vegetables, and decreasing caffeine intake.

Bass and Cox (30) examined the dietary intake of selected nutrients and food components among adult cancer patients at an early stage of treatment. Sixty-two patients with different types of cancer and receiving different treatments kept three-day food records, which were analyzed using the Nutritionist IV computer program. Intakes of cancer patients were compared to intakes of the general population as reported in three national dietary
surveys. Female cancer patients (n = 42) had significantly lower intakes of vitamins A, B12, and E, thiamin and zinc, and significantly higher intakes of beta-carotene, magnesium, copper, and vitamins C and B6 than the general population. The mean intakes of male cancer patients (n = 20) were significantly lower for vitamins A, E, B6 and B12, riboflavin, folate, niacin, and all minerals tested, but significantly higher for beta-carotene than the general population. Female cancer patients' fat intake of 29.2% of kilocalories was significant lower, and mean dietary fiber intake of 12.8 g was significantly higher, than the general population. Female patients' mean caloric intake of 1,480 kcal was not significantly different from intake for the general population. For male cancer patients, mean intakes of protein (66 g), dietary fiber (13.4 g), energy (1,686 kcal), and fat (31.4% of kilocalories) were significantly lower than national survey values.

A literature search revealed only one intervention study related to actual food intake of cancer patients. Menashian et al (31) evaluated 19 patients with different types of cancer who had no mechanical eating problems, no history of having been on a restricted diet, and had not received chemotherapy with cisplatin prior to the study. All had normal oral intake, and did not receive nutrition artificially. All 19 patients, 10 female and 9 male, were receiving cisplatin chemotherapy, which commonly produces intractable nausea and vomiting, and requires the use of high-dose antiemetic drugs. Ten patients received a study diet primarily composed of odorless and tasteless food, consisting of 1/4 cup low fat cottage cheese; 1/2 cup unsweetened apple sauce; 160 cc cream soup, served hot; 90 cc vanilla ice cream; 120 cc gelatin; and 360 cc cola-flavored sweetened carbonated beverage, served with ice.
The study diet was served three times per day as inpatient meals, and totalled approximately 1,650 kcal. 

The nine control subjects selected an entree, vegetable, starch, beverage, fruit, and dessert from the daily menu served for regular, nontherapeutic diets. Nursing staff recorded volume and number of episodes of emesis for each patient; antiemetic medication requests; and the percentage of food served that patients actually ate.

Results indicated that patients in the study group experienced fewer episodes of emesis, resulting in better retention and digestion of food. The authors noted that upon readmission for cisplatin treatment, patients who had previously received the study diet requested it again without prompting from the study team. The authors had designed the study diet based upon their observations that certain foods were tolerated by a wide sample of cancer patients receiving cisplatin, and that these foods were generally odorless and colorless.

Hulshof et al (32) studied 105 cancer patients in the Netherlands. The patients were 28 females with endometrial or cervical cancer, 50 males with bladder or prostate cancer, and 14 males and 13 females with malignant lymphoma, all of whom were treated with chemotherapy and/or radiation therapy. The subjects were studied for 19 weeks as hospital outpatients. The authors used two methods to collect dietary data. First, at the start of the study, a diet history was taken to determine a patient's customary diet over the last two months. Second, the subjects recorded their food intake on two consecutive days at seven points during the study. Each time a diary was completed, the patient completed a questionnaire on eating habits.
Diet histories and food records were analyzed by computer program.

Analysis showed that over the two months prior to cancer therapy, the average daily energy intake varied from 1,875 to 2,740 kcal. Analysis of vitamin and mineral content showed intakes which met or exceeded the Dutch Recommended Dietary Allowances for all nutrients except iron in females. The mean daily intakes of energy, vegetable protein, fatty acids, total fat, polysaccharides, dietary fiber, iron, and thiamin of women with endometrial or cervical cancer were lowest during radiation, but rapidly returned to initial levels or more by two to three weeks after completion of the treatment. Men with bladder cancer undergoing radiation showed only slight decreases in energy and nutrients from usual levels. Energy and nutrient intakes in men with lymphoma who received repeated chemotherapy treatments showed higher values in weeks 7 to 13 during treatment. Women with lymphoma who received the same chemotherapy as the male patients also exhibited an increase in mean energy intake from week 0 to week 3. For all groups of patients, sugar-containing products such as cookies, pastries, and soft drinks, constituted the main source of energy.

The authors found that certain patients went on a "constipating" diet at some point during therapy because of diarrhea. Instead of brown bread, potatoes, coffee, milk, and orange juice, they used white bread, rice, tea, bananas, apples, and black currant juice. When diarrhea was over, usually a few weeks after the end of irradiation, all patients resumed their normal eating patterns.

The authors (32) observed no alarming shifts in energy or nutrient intakes in any of the groups investigated. Only the iron intake in both female groups was an issue of
concern. They concluded that although dietary intake decreased in patients undergoing radiotherapy, it rapidly returned to normal afterwards.

Only four articles were found which dealt with the food intake of terminally ill or palliative care patients. Three articles concerned cancer patients, and one described AIDS patients.

Walsh et al (33) assessed the voluntary dietary intake of 13 hospice inpatients for five consecutive days. Patients were 11 females and 2 males, age 56 to 83 years (median age 74) who had advanced cancer of different types. Standard sized scoops and spoons were used to serve food in small, medium, or large standard portions, depending upon the patient's appetite, and were weighed as served. Individual plate waste by weight was subtracted to estimated individual intake. Foods provided by visitors were not included.

The range of individual mean energy intakes was wide (224 to 2,137 kcal), with a mean daily intake of 1,376 kcal. Individual mean daily intakes of select nutrients were found to be: 44 g protein (11-86); 52 g fat (9-93); 169 g carbohydrate (21-194); 748 mg calcium (268-1,457); 4.8 mg iron (0.5-21.0); and 5 g dietary fiber (0.5-21.0). Compared to recommended amounts, energy, iron, and dietary fiber intakes were low, and calcium intake was high.

Corli et al (34) attempted to quantify the extent of nourishment and variations in food intake during the last weeks of life. The authors devised a new method for measuring food intake, based upon a self-descriptive record in which the patient chose one of five different levels of food intake (a lot, normal, little, very little, nothing). The record was tested on 100 healthy persons to establish a numerical score for each of the five levels of food intake.
The food record was then used with 75 patients, all with advanced tumors requiring palliative treatment, receiving home care assistance. Patients were enlisted for the study as they enrolled in the palliative care center, and completed the records daily to describe the last 24 hours, until the last days of life. Patients also recorded information about physical and psychological conditions.

The weekly mean of the daily food scores was calculated, and data analysis included only patients who survived at least six weeks from the beginning of the study. Groups were compared by ANOVA and Student's t test.

The mean food intake score for patients before palliative care was $3.698 \pm 1.468$, considerably below the normal value of 5.5. Receiving palliative care at home resulted in a statistically significant increase in food intake score, up to $4.484 \pm 1.526$ in the first week, and $4.447 \pm 1.377$ in the second week. This occurred despite the lack of specific treatments to improve appetite.

During the last four weeks of life, food intake steadily decreased even though treatment was carried on. Values for the fourth, third, second, and last week of life were $3.367 \pm 1.483$, $3.100 \pm 1.585$, $2.5899 \pm 1.501$, and $2.424 \pm 1.542$, respectively. All figures were much lower than the normal value of 5.5.

The authors state that their study confirms the current assumption that far advanced cancer patients are undernourished. They were also able to assess how the patient's nutrition was influenced by a home care and palliative care program. However, the improvement in nutrition upon entering the program was transient, since food intake progressively decreased down to very low values in the last month of life.

Feuz and Rapin (35) studied 116 elderly patients with
terminal cancer who were hospitalized until death. Patients included 71 women and 45 men, average age of 76 years (range 61-94), with various types of cancer. Their length of stay in the hospital ranged from 5 to 465 days, with a median stay of 32 days. The authors cite the difficulties which arise when patients exhibit such symptoms as anorexia, weight loss, weakness, and anxiety, and thus may be given artificial nutrition and hydration which can be invasive, futile, and controversial. The authors say that they initiated this study to find a better approach to this difficult problem, and to improve the quality of life for elderly patients with terminal cancer. The purpose of their study was to determine whether certain modifications in therapeutic approaches would have a beneficial effect on nutrition behavior. They performed a prospective, qualitative study and did not measure the daily oral energy and nutrient intake of patients.

All patients were interviewed the day after admission and each week thereafter until death. The interview aimed to determine a patient's food preferences and dislikes; subjective intolerances to certain foods; and difficulties in chewing and swallowing. For each patient, a detailed record was kept of the initial interview, plus the patient's requests, dietary modifications, and reactions to these modifications. The first diet plan included three main meals and two snacks each day. Patients were evaluated clinically using simple parameters such as hematocrit, sodium, total protein, and serum albumin values.

Results revealed that 107 subjects (92%) had meals until the day they died. The remaining nine subjects stopped eating an average of 3.5 days before they died. For 51 patients (44%), the diet plan established at the
time of the first interview remained unchanged throughout the stay. The diet plans of the remaining 65 patients needed various modifications such as adapted texture, decreased or increased portion size, or adaption to some medical condition which developed after the patient's admission. Fifteen patients (13%) refused food containing meat.

Weber and Dalton (36) presented three case studies on the food habits of three terminally ill men with AIDS. This article is reviewed here since AIDS patients may exhibit weight loss and wasting symptoms as do terminal cancer patients. This qualitative study focused on the changing food habits of three homosexual men with AIDS living in New York City. Their lives before and after diagnosis were discussed at length. The authors attempted to determine how food habits changed during the terminal illness of AIDS. The three men were selected, extensively interviewed, and frequently observed for a six-month period. Food behavior patterns, body weights, medication use, and physiologic changes were tracked.

The authors found that while basic food patterns did not change, the content of meals did change. These changes were not consistent among foods or in relation to various stages of illness. Comfort and ease were important, and food choices changed to include foods that were remembered with fondness. Also, the most important condition related to food intake that emerged from the study was the social isolation of the participants: as isolation increased, food intake decreased.
Nutrient and Energy Requirements for the Cancer Patient

All patients, including those with cancer, have specific nutrient needs. No single diet regimen or feeding method is appropriate for all individuals. Thus, before any recommendations are made for a patient, his nutrition status should be assessed initially. Also, nutrition status should be reassessed periodically or as treatment proceeds, and nutrition care plans adjusted as necessary (37).

The usual method of nutrition assessment to determine nutrition status is the evaluation of information from four sources: dietary intake, biochemical data, anthropometric measurements, and clinical signs of nutrient deficiencies. However, assessment of nutrition status alone will not provide information about the cause of the nutrition problem, which must be determined before the malnourished state can be corrected (37).

Coulston and Darbinian (37) recommend the standard nutrition assessment for cancer patients. According to these authors, an estimation of energy and major nutrient intake is essential, and can be obtained by using a 24-hour diet recall on admission and by periodically using two- or three-day food intake records for in- or outpatients. Anthropometric assessment should include height, weight, weight history, and triceps skinfold and midarm circumference measurements. Biochemical tests should include any test specific for a nutrient of concern, and serum albumin and transferrin measurements. The authors caution that these serum proteins may be depressed as a result of cancer therapy or the disease process itself. Other parameters, such as hematocrit, hemoglobin, delayed hypersensitivity skin tests, and lymphocyte numbers may show abnormal results not only from malnutrition, but also
from cancer treatment or disease. Thus, certain standard tests may have limited use in the nutrition assessment of cancer patients.

Cimino (38) simplifies the nutrition assessment for advanced cancer patients to include: (1) the patient's present height and weight, and, if possible, the patient's pre-illness weight and preferred weight, as compared to standard tables; (2) the presence and frequency of factors that impair oral food intake, e.g., nausea, vomiting, diarrhea, and pain; (3) psychosocial data, such as the patient's emotional state and family situation; (4) any preexisting medical conditions that result in impaired intake, e.g., surgery or cardiovascular, renal, or liver disease; and (5) the patient's food preferences. This information would help the dietitian plan short term goals directed toward achieving and maintaining reasonable body weight, electrolyte homeostasis, and adequate hydration.

Cimino (38) emphasizes that sophisticated and expensive tests are unnecessary. Even weight status may be meaningless because of fluid retention or dehydration. Other simple parameters can include physical examination for well-known signs of nutrient deficiency, such as skin changes, edema, and lingual papillation.

Daly and Shinkwin (39) provide a simple, practical definition of significant malnutrition that can be applied clinically. It includes recent unexplained weight loss of 10% or more of body weight; a serum albumin of less than 3.4 g/dl; and a serum transferrin of less than 190 mg/dl. They believe that any combination of two of these criteria is an indication for nutrition support.

Following nutrition assessment, the first decision to be made is how to nourish the patient. Although more than thirty nutrients are necessary for human nutrition, energy
and protein needs are the most difficult to provide clinically because of the large volume required. The initial focus of nutrition care plans must be on an adequate energy and protein intake, based on the nutrition requirements established for the patient (37).

There is speculation about whether the most detrimental factor in weight loss in the cancer patient is an increased energy expenditure or a decreased energy intake. There are conflicting data from clinical and laboratory studies as to the degree of increased metabolism on the part of the cancer host. It has been suggested that different tumors may exert different influences on resting metabolic expenditure (RME). In addition, variations in the degree of weight loss in cancer patients have been considered to influence RME (40).

Young (41) reviewed the literature about energy requirements in the cancer patient, and reported on variations in basal metabolic rates from -10 to +120% of normal in a population of cancer patients. Merrick et al (40) studied post-absorptive resting energy expenditure (REE) in 21 patients with colorectal cancer. None of the patients had received radiation therapy, chemotherapy, or surgery before entering the protocol. There were nine male patients, average age of 61.2 years (range 57-70) and a mean weight of 72.7 kg (49-95 kg). The twelve female patients had an average age of 75 years (range 54-88) with a mean weight of 68.2 kg (43-77 kg). Energy intakes were measured based on total parenteral nutrition (TPN) volume infused, and resting metabolic expenditures (RMEs) were determined by indirect calorimetry. The predicted RMEs were calculated using the Harris-Benedict equation (42) which is based on the patient's age, weight, height, and sex. Results indicated that the cancer patients did not
have an increased RME in the postabsorptive state (overnight fast or while receiving less than 500 kcal of glucose), since their predicted and measured expenditures were essentially the same. Merrick et al. (40) mention three other studies in which certain other cancer patients exhibited a significantly increased RME, and those authors attribute the difference between their results, and the results in the three studies, to the fact that 11 of their 21 subjects had metastases to the liver.

Lundholm (4) reviewed a number of studies related to energy expenditure in cancer patients, and also concluded that results were contradictory. He states that it is quite clear that elevated energy expenditure occurs in numbers of weight-losing cancer patients, but some authors have failed to detect such differences. He attributes such discrepancies to differences in investigative approaches with regard to the use of reference patients, and the degree of sensitivity, stability, and reproducibility of the technology used to measure energy expenditure.

To determine a cancer patient's total energy needs, several authors (37,39,43) suggest using the Harris-Benedict equation to calculate basal energy expenditure (BEE), plus a percentage, depending upon the disease condition and the activity level. Coulston and Darbinian (37) state that general caloric requirements of most patients will be 1.5 to 2.0 X BEE to facilitate repletion and minimize catabolism.

In contrast, Chory and Mullen (44) do not advocate using the Harris-Benedict equation to calculate recommended energy requirements for the cancer patient. They state that these classic formulae, and other formulae based solely on weight or body surface area, were derived on healthy subjects. These formulae assume normal body
composition and uniform intensity of metabolic activity per unit of body mass. Neither assumption is correct in malnourished cancer patients or any hospitalized patient. These authors use indirect calorimetry to measure REE, the major component of total daily energy expenditure, which also includes expenditure secondary to musculoskeletal activity. Their standard caloric prescription for weight maintenance is 130% of measured REE in nonprotein kilocalories. Also, nonprotein energy intakes in excess of 110% of measured REE are necessary for possible energy balance and subsequent repition of adipose stores.

The attached table lists requirements for selected nutrients which have been published in the literature.

Recommendations to Increase Oral Food Intake

The importance of improving nutrition status to improve the prognosis or survival of the cancer patient is still unproven. Yet, many authors stress the importance of feeding or providing nutrition support to the cancer patient. This section will review some recommendations given in both the scientific literature and in publications for laypersons to help the cancer patient improve oral intake of food and fluids. The provision of nutrition by artificial means will be discussed in chapter 7.

Several authors provide suggestions to dietitians who are responsible for the nutrition of cancer patients. Cimino (38) states that the clinical dietitian, with the help of food service personnel, should exploit every idiosyncrasy of the patient to improve energy intake and allow the patient to savor those aspects of eating that are still pleasurable. Each patient's diet must be individualized. Breakfast is known to be the most popular
Table: Recommendations for intakes of select nutrients for cancer patients (with references in parentheses)

<table>
<thead>
<tr>
<th>NUTRIENT</th>
<th>RECOMMENDATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protein</td>
<td>1.0 - 1.5 g/kg body weight for maintenance (44)</td>
</tr>
<tr>
<td></td>
<td>1.5 - 2.0 g/kg for protein-depleted patient (44)</td>
</tr>
<tr>
<td></td>
<td>1.5 g/kg (37)</td>
</tr>
<tr>
<td></td>
<td>1.5 - 2.0 g/kg (45)</td>
</tr>
<tr>
<td>Energy</td>
<td>44 kcal/kg for males (45)</td>
</tr>
<tr>
<td></td>
<td>40 kcal/kg for females (45)</td>
</tr>
<tr>
<td>Long-Chain Fatty Acids</td>
<td>maximum 1.5 g/kg/day (39)</td>
</tr>
<tr>
<td>Vitamins</td>
<td>meet RDAs (39)</td>
</tr>
<tr>
<td>Sodium</td>
<td>60 - 140 meq (39)</td>
</tr>
<tr>
<td></td>
<td>60 - 120 meq (44)</td>
</tr>
<tr>
<td>Potassium</td>
<td>60 - 100 meq (39,44)</td>
</tr>
<tr>
<td>Chlorine</td>
<td>60 - 120 meq (39,44)</td>
</tr>
<tr>
<td>Magnesium</td>
<td>8 - 10 meq (39,44)</td>
</tr>
<tr>
<td>Calcium</td>
<td>200 - 400 mg (39,44)</td>
</tr>
<tr>
<td>Iron</td>
<td>1 - 2 mg (39,44)</td>
</tr>
<tr>
<td>Phosphorus</td>
<td>300 - 400 mg (44)</td>
</tr>
<tr>
<td>Water</td>
<td>2000 - 2750 ml/day with additional needs (46,47):</td>
</tr>
<tr>
<td></td>
<td>with fever: 500 - 1500 ml/day</td>
</tr>
<tr>
<td></td>
<td>with moderate perspiration: 500 ml/day</td>
</tr>
<tr>
<td></td>
<td>with profuse perspiration: 1000 ml/day</td>
</tr>
<tr>
<td></td>
<td>30 ml/kg body weight or 1400 ml/m² body surface area adjusted for deficits,</td>
</tr>
<tr>
<td></td>
<td>losses, overload, or physical symptoms (44)</td>
</tr>
</tbody>
</table>

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meal among cancer patients. If breakfast or some other meal is especially appealing to the patient, that meal should be emphasized, and breakfast-type foods can be offered at all meals. An anorectic patient should be given the opportunity to order and to change requests spontaneously. Food odors should be enhanced or minimized, depending on the patient's preference.

Cimino (38) suggests that small, frequent, high-calorie meals might be more appealing. Care should be taken not to offer foods and beverages that the patient finds offensive, and the patient should be encouraged to eat and drink slowly.

Wade and Jain (48) offer suggestions for a palliative care unit. Cancer patients who are ambulatory should be encouraged to eat with other patients or with family members to maintain social interaction. Certain food items such as soups, broths, milk, cola beverages, and regular, soft, and pureed meats and vegetables, can be kept available at all times. Enteral supplements should be made available 24 hours per day.

Maillet and King (49) emphasize the importance of heeding patient food preferences and avoiding patient food aversions and intolerances. Dietary restrictions based on rationales for prevention or treatment of chronic disease should be liberalized or eliminated, except when physical discomfort results. Offer small frequent feedings of easy to digest foods or nutrition supplements; provide assistance in the feeding process; and have easily available, calorie-dense foods on hand.

Kelly (50) provides lists of specific suggestions according to presence of certain symptoms in the cancer patient, including decreasing appetite, taste changes, pain, mouth sores, dry mouth, swallowing difficulties,
nausea and vomiting, and constipation. Some general rules are to let the patient eat immediately upon feeling capable of ingesting food; to provide a variety of foods and beverages to improve nutrition and avoid boredom; and to watch for adequate vitamin and mineral intake. Some high protein foods she suggests are: eggs, fish, beans and peas, soybean products, peanut butter, sunflower seeds, cheese, and milk. Some calorie-dense additions are: butter or margarine, gravy, sauces, cream, milk shakes, salad dressing, ice cream, whipped cream, and granola bars.

Stephany (51) provides some specific suggestions for terminally ill patients: offer several small meals each day instead of three large ones, and, most importantly, avoid nagging the patient about food.

There are four booklets about feeding the cancer patient available from the American Institute for Cancer Research (52), the National Cancer Institute (53), the American Cancer Society (54), and Ross Laboratories (55).

The American Institute for Cancer Research booklet (52) provides suggestions to help the cancer patient increase food intake while undergoing surgery, radiotherapy, chemotherapy, and biological response modification (bone marrow transplants or use of interleukins). The booklet gives an overview of some nutrition-related problems associated with each treatment modality. It also gives suggestions for improving eating in the presence of common symptoms such as appetite changes, constipation, diarrhea, fatigue, or dumping syndrome.

The National Cancer Institute publication (53) reviews how to manage eating problems in the presence of cancer symptoms and cancer therapy side effects, and gives specific information about healthy snacks, and how to
increase protein and energy in the patient's diet. This booklet reviews the use of special diets, such as clear liquid, full liquid, soít, low residue, and low lactose; and provides over forty recipes suitable for the cancer patient.

The American Cancer Society booklet (54) reviews ways to improve nutrition in the presence of symptoms and side effects which adversely affect food and fluid intake. In this booklet, nutrition information is scattered throughout, and relates to the specific problem under discussion.

The booklet from Ross Laboratories (55) reviews cancer treatments, symptoms, and side effects, and mentions ways to add energy and protein to the patient's diet. This company devotes a portion of their booklet to the use of their commercially available supplements, providing descriptions and recipes for their use.

The use of supplements, especially liquid supplements such as Ensure or Sustacal, is advocated by many experts, and such liquid diets are increasingly being used (56). However, oral consumption of enteral formulae frequently becomes monotonous in taste and consistency, and loses palatability. Also, many patients will be unable to consume 2,000 to 2,500 ml of liquid to meet their energy needs, especially if they are anorectic or volume-sensitive (37,56).

A different perspective on feeding the cancer patient or other terminal patients is provided by Haller (57), a chef who works with hospice patients. He suggests using "fresh, whole, and puré" foods which are simple, quick, and inexpensive to prepare. He emphasizes orange foods, high in vitamin A; green foods, high in vitamins A and C, and potassium; and purple foods, high in potassium. When a
patient asks, "What should I eat?", Haller suggests, "Lots of orange colored foods, lots of dark greens, as many calories as you can, and as many non-meat proteins". Examples of dishes he recommends are: fish soup; sweet potato frappe; pureed foods put through a pastry gun; greens sauteed in olive oil, garlic, and chicken stock; and peach custard.
REFERENCES


Key Issues Discussed in Part II:

- The relationship between nutrition and cancer which is already present can be examined from two perspectives: the effects of the presence of cancer on the patient's nutrition, and the role of nutrition in the cancer patient's prognosis and treatment.

- Some common symptoms and conditions which result from cancer and which can greatly influence food intake and nutrition are: anorexia, nausea, vomiting, constipation, diarrhea, and taste changes.

- Food intake is also influenced by the use of surgery, chemotherapy, or radiation therapy; of drugs to control symptoms; and psychosocial factors.

- Providing nutrition support has not been proven to influence clinical outcome in cancer patients, yet many health care professionals stress the importance of feeding.

- Little research exists about what cancer patients, especially the terminally ill, actually eat; most research focuses on food preferences and aversions.

- Each terminally ill cancer patient has unique nutrition requirements, and individual nutrition care plans must be formulated.

- Dietary restrictions should be eliminated, unless it results in physical discomfort for the patient.
PART III. STARVATION AND DEHYDRATION

Introduction:

Chronic hunger and famines have afflicted humankind all throughout history, up to the present, as a result of poverty, droughts, and war. Interest in starvation is ancient, and experimental studies of food deprivation began around the turn of the century (1,2). Starvation can be defined as the condition of being without food for a long period of time (3), and dehydration can be defined as a loss of body water (4).

As explained in Part II, many terminally ill patients and patients with cancer will exhibit anorexia, cachexia, and malnutrition for a variety of reasons, and may have very poor intakes of food and fluids. Such patients can be considered starved, malnourished, or dehydrated, and some health professionals may use artificial nutrition and hydration, even for the dying patient. The metabolic effects of starvation allow humans to adapt and to live for months without any food (1,2), so even patients with very low intakes may survive for extended periods of time.

This section will explore starvation and dehydration in humans. Chapter 5 will discuss starvation and dehydration in normal humans, and will focus on symptomatology, rather than on biochemical or metabolic changes and adaptations resulting from decreased food and fluid intake. Chapter 6 will discuss the effects of decreased food and fluid intake on terminally ill patients, again focusing on symptoms. Clinical and ethical issues related to artificial feeding methods will be discussed in Part IV.
Chapter 5: Starvation and Dehydration in Normal Humans

Starvation

According to Levenson et al (5), the description of some of the overall physical, functional, and psychological effects of severe food deprivation can be found in early writings, but actual prospective studies of men subjecting themselves to voluntary food deprivation began around 1866 in Italy, the U.S., France, and Germany. These early investigators found that the length of life during starvation depended upon the quantity of fat present in the organism at the start of the fast. Benedict (6) studied the effects of total nutrient deprivation, other than water, in a professional faster from Malta for 31 days. There was a gradual drop in the subject's energy expenditure from an average of 1650 kcal/day during days 1 to 7, to an average of 1290 kcal/day during days 15 to 21, and it remained at about that level for the next 10 days. It was found that a month of starvation did not impair the subject's mental or physical productivity.

Wars have always exacerbated the problem of supplying adequate food to the population, and have provided opportunities to study the effects of undernutrition on large numbers of people. Thus, during and after World War II, several studies and publications appeared describing starvation in Western Europe. Three of the most significant studies will be reviewed here.

In 1940, the Nazis sealed off the Jewish ghetto in Warsaw, Poland, condemning several hundred thousand people to death by starvation. A group of Jewish physicians decided to make a careful medical investigation of the clinical, metabolic, and pathological consequences of hunger and starvation. The patients were carefully
selected to represent pure hunger disease with no complicating infections. The study (7) ran from February to July, 1942, and involved 100 adults and 30 children on an 800 kcal diet of mostly carbohydrates. It was found that the first signs of even a short period of hunger or of a drastic change in the diet results in constant thirst, and a persistent increase in urinary output of 4 to 5 liters. Other early complaints are nocturia; dryness of the mouth; rapid weight loss; and a constant craving for food. With prolonged hunger, these symptoms diminish, and the patient experiences general weakness; sleepiness; inability to sustain even the smallest physical effort; a constant feeling of cold; apathy; depression; sometimes aggression; and a lack of initiative. Toward the end of hunger disease, the only complaint is of complete exhaustion.

Other clinical symptoms include the appearance of very bulky stools; mucous and bloody discharge from the colon; edema, first appearing in the face, feet, and legs, and later affecting the whole body; aches and pains in the ribs, sternum, pelvis, and lower extremities; nervousness and anxiety; amenorrhea; and impotence. The skin color is characterizedly pale or cyanotic, with brown pigmentation around the neck, rump, sides of the torso, and on the back of the arms and thighs. The face becomes cachexic and brown; the skin is chapped, dry, wrinkled, thin, atrophic, and devoid of elasticity and turgor. The body temperature is low; extremities are cold; sweat glands atrophy; and hair and fingernail growth is abnormal. Skeletal muscles become slack and atrophic, and all movements are slow. Faces are expressionless and pale; lens changes occur in the eye; the tongue is coated; and patients complain of a burning sensation of the tongue.
The incidence of tuberculosis was increased, possibly due to atony of the lungs, decreased muscle tonus, impaired ventilation, and poor blood circulation. Other respiratory problems include: bronchitis; bronchopneumonia which is almost asymptomatic; and pseudopneumonia.

Cardiovascular changes include asthenia; reduced cardiac output; impaired peripheral blood circulation; coldness, pallor, and impaired thermal adaptation. There is a tendency toward osteomalacia; spontaneous breaks of the neck of the femur; and slow healing of spontaneous breaks. Other problems include: muscle spasms; polyneuritis; contractures of the extremities; apathy, depression, poor thinking, and incoherence. The authors describe the dying process as "...slow and gradual, like death from physiological old age. There is nothing violent, no dyspnea, no pain, no obvious changes in breath or circulation. Vital functions subside simultaneously. Pulse rate and respiration rate get slower, and it becomes more and more difficult to reach the patient's awareness, until life is gone."

Another large study (8) of starvation was done in the Netherlands during World War II. During the German occupation from 1940-1945, the Netherlands experienced a serious famine and many people deteriorated to an advanced stage of starvation. The Netherlands government conducted a study of the western part of the country, which was most seriously affected. Both the famine victims, and the refeeding process which took place after the Allies liberated the country were studied. During the famine, the average daily food intake was about 1600 kcal in 1944, and fell to as low as 500-600 kcal. Common symptoms of starvation are edema; loss of 15 to 20% of total body weight; diarrhea; fatigue and weakness; muscle pain;
menstrual irregularities or amenorrhea; redness and swelling of the lips; dry and cracked skin; patchy areas of brown pigmentation on hands, arms, chest, and in the mouth; and pallor. The chief complaint is hunger, and appetite is rarely diminished or absent, except in very severe cases. Another general complaint is of physical and mental fatigue, resulting in clumsiness, the inability to concentrate, and memory decline. Other common complaints are: pain in the limbs; back pain; burning sensations in hands and feet; polyuria and nocturia; dropsy; coldness; dry and painful mouths with difficulty and pain on swallowing; and impotence. Patients may show a lack of initiative and energy; apathy; irritability; paranoid traits; delirium; and hallucinations. Muscles are very atrophic and weak; the tongue is red with painful patches; mouth and pharyx are ulcerated; and pain is present in bones, not joints. A "hunger osteopathy" develops which resembles rickets or osteomalacia. Cardiovascular symptoms include: dyspnea; palpitations; dizziness; anemia; bradycardia; and a tendency to hypotension.

A third study, done in the U.S. by Keys et al (9) in 1944-1945, was another attempt to document the effects of starvation and refeeding because of events taking place in Europe. The subjects were 36 males who were conscientious objectors. Thirty-two men completed a 12 week control period, 24 weeks of semi-starvation at about 1570 kcal/day, and 12 weeks of restricted rehabilitation. During semi-starvation, two meals per day were served, and the diet was designed to represent the foods used in European famine areas. The 32 subjects were divided at the beginning of the 12 week rehabilitation period into three subgroups. The caloric, vitamin, and protein content of the rehabilitation diet was different for each subgroup.
The authors observed that undernutrition quickly results in numerous physiological changes which become progressively far-reaching as the condition continues. Bradycardia is observed, with a slow heart rate at both rest and work. Reduced peripheral circulation results in mild cyanosis, cold skin, and increased circulatory time. Venous pressure falls and edema results. Other water balance problems are polyuria, nocturia, and a marked salt hunger; thirst is not often a complaint. The starving person feels cold and weak, both physiologically and subjectively; he acts dull and insensitive; some senses are heightened; and reactivity to stimuli is diminished. The subjects show greatest deterioration in the symptoms of tiredness, appetite, muscle soreness, irritability, apathy, hunger pain, ambition, self-discipline, and concentration. Moodiness, depression, and lack of self-discipline become more severe as semi-starvation progresses. Hunger pain remains relatively constant, while dizziness, nausea, and salt craving show reversed trends as semi-starvation continues.

Other physical changes are: unsteadiness and uncertainty of footing; gradual wasting of muscle and subcutaneous adipose tissue; muscle cramps and soreness; jarring of knee joints when walking; intolerance to cold temperatures; vertigo, dizziness, and momentary blackouts on rising from lying or sitting positions; and a reduction in strength and endurance. The authors found that, unlike in total starvation, in which the sensation of hunger disappears in a matter of days, in semi-starvation there was no reduction of hunger.

More recently, Bishop and Mallie (10) describe the process of starvation and death in the Irish hunger strikers in 1980-1981. One prisoner, Bobby Sands, died in
May, 1981 on the 65th day of his fast. A prison physician noted the stages of the fasters' decline. After a few days without food, the initial hunger pangs cease, and extreme nausea occurs. The prisoners' bodies react violently to the impurities in tap water, and they have difficulty keeping down even mineral water. After a week, bowel motions cease, and an eye condition called nystagmus occurs, resulting in an inability to focus the eyes, and a wandering gaze. This, in turn, affects balance, creating a form of sea-sickness. For the first six weeks, the prisoners vomit repeatedly, and the retching stops around the 45th day. The prisoners can now hold down fluids, seem more lucid, and demonstrate signs of recovery. During the last stage of decline, brain damage develops, the fasters start to slip in and out of coma, and are rambling and incoherent when conscious. Blindness, unconsciousness, and, rarely, convulsions, occur during the final stage.

**Dehydration**

Many of the articles about dehydration in humans discuss this condition in older adults, who can easily become dehydrated (11,12). Some common causes of dehydration in elderly persons are: an imposed water restriction preparatory to laboratory procedures; the presence of fever, infection, or diarrhea; the use of diuretics; the presence of a syndrome of inappropriate antidiuretic hormone secretion due to malignancy, central nervous system disease, or drugs; refusal to drink because of depression; a natural decrease in total body water with aging; vomiting; diabetes insipidus; the use of high-protein feeding solutions; a reduction in renal concentrating ability with aging; and an inability to obtain water for themselves because of stroke, dementia,
immobility, or delirium (11,13-19).

The need for fluids is second only to the need for oxygen (12). Leaf (11) explains that dehydration is a state of water loss or dryness, and commonly refers to two fluid and electrolyte disorders. The first is sodium depletion, in which there is a decrease in sodium and water, and the second is water depletion or free water deficit. Both result in a reduced body water content. When sodium depletion occurs, there is usually a reduction in extracellular fluid volume. Functional disturbances result from interference with circulation due to decreased plasma volume, and when severe, increased viscosity. This condition is common in patients treated with diuretics and in those with bowel obstruction, diarrhea, vomiting, renal sodium-wasting syndromes, or excessive sweating. Such patients may replace water, but not sodium, so that total body water may actually not decrease. Billings (4) calls this sodium-deficient state hyponatreemic or hypotonic dehydration, which can cause neuropsychiatric manifestations such as weakness, lethargy, restlessness, confusion, delirium, stupor, and coma. Also, thirst may not be present in these patients.

Leaf (11) explains that the second type of dehydration is primary water loss, which may occur with a drastic reduction of water intake, or with loss of water from sweating or urinary water excretion in excess of sodium loss. The sodium concentration rises in the extracellular compartment, drawing water osmotically from the intracellular fluids. Functional disturbances are related to central nervous system dysfunction. Billings (4) calls this condition hypernatremic or hypertonic dehydration, which is characterized early in its development by intense thirst. This type of dehydration can also cause mental
status changes, beginning with mild confusion and progressing to coma. Fatigue, muscular weakness, and low-grade fever may also occur with hypernatremic dehydration.

Other authors (13,20-22) mention symptoms which can be present in elderly persons with dehydration: confusion, lethargy, or coma; irritation of muscles and the central nervous system leading to seizures; renal failure; decreased skin turgor with skin breakdown; increased falls and related injuries; and constipation with impaction.

Snyder et al (19) reviewed hospital records for 15,187 consecutive hospital admissions for patients who were 60 years of age or older, and found that 162 patients (1.1%) were hypernatremic. Of that 162, 57% had become hypernatremic in the hospital, and the remainder were hypernatremic at admission. More than forty causal factors were identified, and the most frequent primary causes were: complications of surgery (21%); febrile illness (20%); infirmity with inability to obtain water for oneself (11%); and diabetes mellitus (11%). The overall mortality rate was 42%, and at discharge, the rate of morbidity was at least 38%. Study patients with higher peak serum sodium levels were more likely to have a severely depressed state of consciousness, and those patients with the most severely depressed state of consciousness were less likely to survive.

Lavizzo-Mourey et al (23) studied 339 elderly nursing home residents who developed an acute illness requiring admission to a hospital. The patients had an average age of 84.3 years; had an average of 6.1 chronic diseases; and received a mean of 5.1 medications for those diagnoses. On admission to the hospital, they averaged 2.8 acute diagnoses. On the basis of serum sodium level, and blood urea nitrogen to creatinine ratio, 173 patients were
designated controls (not dehydrated), and 91 were designated cases (dehydrated). Several trends emerged: there was a greater proportion of females among the cases than among the controls; the more severe cases had more chronic diagnoses than the less severe cases or controls; severely dehydrated patients took more medications; and dementia or organic brain syndrome was diagnosed in 60% of cases and controls. Factors for increased risk of dehydration were found to be: requirements for tube feeding or assistance with feeding; requirements for assistance with transfers or ambulation; being bedridden and requiring a skilled level of care; having more than four chronic diseases; taking more than four medications; using laxatives; having a diagnosis of cerebrovascular accident; and the presence of infections, such as pneumonia, urinary tract infection, or sepsis.
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Chapter 6. Terminal Starvation and Dehydration

Terminal Starvation

Starvation may be an inappropriate term when applied to the dying patient. Billings (1) states that starvation is a word with powerful symbolic meaning, suggesting withholding, neglect, punishment, and suffering. He suggests "fasting" or "semistarvation" as more accurate terms to describe the nutrition status of patients with feeding difficulties. The symptomatology and results of starvation and semistarvation in normal humans were described in Chapter 5. However, the medical consequences of nutritional deprivation in a severely ill patient who is close to death are difficult to judge (1). Also, the assumption that nutrition support will benefit terminal patients has not been clearly established (2,3). Billings (1) emphasizes that the physician must consider how each particular patient feels when unable to eat, since the patient might be debilitated, anorectic, not fully alert, and have a poor quality of life. This author believes that very little suffering can usually be attributed to food deprivation, especially in the presence of anorexia. Rather, patients might be troubled by food craving; the loss of pleasure in eating; concern about not eating properly; weight loss with changes in physical appearance; weakness; or postural hypotension.

The problem of deciding to provide nutrition for the dying patient may not be a medical issue, but rather a matter of the symbolic importance of food. To many, providing food and fluids symbolizes care and compassion for another person, and families often use food to express their love for, and desire to help, the patient (1,2,4-6). In general, providing appropriate nutrition intake for the
dying patient frequently improves her sense of well-being and quality of life, at least for a while (4). Oral food should not be denied, but simply made available as the patient requests or tolerates it (7). However, weakness and diminished intake, either abrupt or gradual, are common changes as death approaches (4). Several authors (1,2,4,7-9) believe that the dying patient loses interest in food, and finally is unable to naturally ingest food and water. This is an adaptive process that allows the patient to die with less suffering, and aggressive nutrition support may result in more harm than good.

The process of dying without artificial feeding is described in the literature. Sullivan (3) states that it is possible to predict the clinical course of an individual dying with starvation and dehydration. Most patients will be debilitated from an underlying illness that has robbed them of bodily fat reserves, and thus reduced their ability to survive. Yet, death may not come quickly. When significant adipose stores are present, and renal function is preserved, survival without food and water can continue for weeks. Fasting patients will not be likely to experience pain from food or fluid abstinence. Rather, mild euphoria can occur, accompanied by an increased tolerance for pain. Death can occur from many causes, such as arrhythmia, infection, circulatory collapse, or cardiac arrest, and the clinical course should be rapid. Sullivan believes that it is senseless to continue fluids after a decision has been made to discontinue food.

Schmitz and O'Brien (8), in sharing their experiences with hospice patients, state that as the patient spontaneously decreases food intake, nausea, vomiting, and abdominal pain decrease, especially where there is a bowel obstruction, liver disease, or malignant ascites. They
also state that after the decision is made not to use artificial feeding, many patients experience a sense of relief and a renewed sense of control when they do not have to force themselves to eat under threat of tube feeding. These authors emphasize that artificial feeding up until death generally increases patient discomfort.

Terminal Dehydration

As the dying process continues, the intake of food is no longer a consideration, and hydration becomes the focus (8). Much more literature is devoted to terminal dehydration and its effects than to terminal starvation. Many articles are based on personal observations and perceptions of health care professionals who attend dying patients, and a few authors have published qualitative and quantitative research.

As death approaches, the body's systems operate less and less effectively, and patients gradually lose their desire to drink (10). Dehydration in terminally ill patients results from inadequate fluid intake; gastrointestinal and renal fluid loss; normal fluid loss from the skin and lungs; and from failure to replace these losses (11,12). Such patients usually present with symptoms of both hypo- and hypernatremia (12).

In current practice, physicians often provide intravenous (IV) infusions to dying patients in the belief that dehydration and electrolyte imbalance are painful and stressful conditions (9,11,13). A dying patient on an acute medical-surgical unit who stops eating and drinking may automatically have an IV inserted without consideration of its potential benefits or detrimental effects (6,14). Also, in the home setting, families may request hospital admission for a patient who stops eating and drinking, with
the belief that IV fluids may postpone death (6). However, there is no research evidence to support the conclusion that providing fluids prolongs life (15). Physicians may also fear that not providing artificial hydration may be interpreted as abandoning the patient or as malpractice (11,16). Brooker (9) calls the IV in the dying patient more of an expression of the urge to provide care than a means of actually achieving it.

Micek et al (17) conducted a survey of 103 physicians to determine how strongly they favored the use of IV fluids for the dying, comatose patient. A hypothetical case study and five questions were presented to the subjects, and 73% of the physicians wrote appropriate IV orders for a comatose, dying patient. Of these respondents, 84% would restart the IV if it infiltrated, and 71% would continue the use of the IV after the patient had remained in a coma for three days. Forty percent would use an invasive means to secure an IV route.

The remaining 27% of physicians initially wrote IV orders that would not maintain the hydration of the hypothetical patient. Of these respondents, 64% thought that the IV should not be continued if the patient's condition had not improved after three days. This study shows that the vast majority of the surveyed physicians would start the IV because it is traditional, leading the authors to conclude that the IV is a standard therapy firmly entrenched in medical practice.

In a similar study, Marin et al (18) surveyed 448 doctors and found that 53% would administer IV fluids to a comatose patient with widespread, metastatic cancer; 83% would resize the cannula as required; and 26% would insert a central venous line if necessary. Collaud and Rapin (19) surveyed 397 physicians, using a questionnaire describing
hypothetical cases of dehydration in an elderly terminal cancer patient. Results indicate that 28% of physicians would use artificial hydration in conscious but dying patients, and 44% would choose this treatment for comatose patients.

House (14) surveyed 41 doctors and nurses in two hospices and a hospital to determine their opinions about hydration of terminal patients. The author found that doctors and nurses in a hospital setting feel strongly in comparison to hospice staff about maintaining hydration, and it seems that intravenous infusion (IVI) is commenced because it is traditional. Doctors who advocate starting an IVI would re-site it if tissued; 20% would consider a central line; and 40% would continue the IVI once started. Of the hospital nurses, 43% would encourage resiting it if tissued, and 43% feel that the patient suffers if hydration is not maintained. Some other observations made by the author were that hospital staff may allow their own fears to get in the way of what is best for the patient; junior doctors appear more likely to intervene with treatments than senior doctors; and hospice staff accept the patient's imminent death and do not appear to feel the need to prolong life. House concludes that there are clearly differences in the approach to hydration of terminal patients between hospital staff and hospice staff.

Despite the fact that many physicians indicate that they would use artificial hydration in dying patients, some authors provide information based on their observations and experiences which suggests that hydrating the dying patient may have adverse effects. In Billings' (1,12) experience, thirst and dry mouth are the only seriously troubling and commonly encountered symptoms in dehydrated terminally ill patients. He states that fluid depletion in dying patients
should be regarded as a disorder with relatively benign symptoms (12). Cox (7), who practices medicine in hospice and geriatrics, concludes that dehydration does not cause pain and suffering in the dying patient. He believes that there seems to be a major difference between terminal dehydration and acute water deprivation of an otherwise healthy person.

Schmitz and O'Brien (8) note the following benefits to the dying patient who is dehydrated: (1) lessened urinary output, with less incontinence or less struggling with commode and bedpan for weakened patients; and (2) decreased pulmonary secretions, resulting in less coughing, less congestion, less shortness of breath, less mucus, and less gagging and choking for patient with swallowing difficulties or extreme weakness. Schmitz (4) states that patients who are dehydrated and remain alert do not seem greatly disturbed. They may note their increased weakness, but generally experience less discomfort than patients who receive hydration. Printz (20,21) also concludes from her experience that dying patients are more comfortable with less hydration, and appear to be in less distress and aware of less pain than hydrated patients. Printz postulates that ketones produced during caloric deprivation may induce an anesthetic effect, or that pain-relieving substances, possible opioid peptides, are produced in increased quantity when a person is deprived of food and water. She states that the range of reported sensations, other than those resulting from the primary disease, vary from no distress and possible analgesia to lethargy, weakness, dry mouth, thirst, restlessness, and nausea.

Zerwekh (22,23), a hospice nurse, believes emphatically that fluids should not be given routinely to all patients. She notes the following advantages of
dehydration to the dying patient: (1) decreased urine output results in less need for the bedpan, urinal, and catheter, and less bedwetting; (2) decreased gastrointestinal fluid results in less vomiting, especially in patients with bowel obstruction; (3) decreased pulmonary secretions result in less coughing and congestion; (4) decreased pharyngeal secretions reduce choking and drowning sensations in the patient with swallowing difficulties; and, (5) as body fluids decrease, peripheral and pulmonary edema decreases, possibly decreasing pressure on tumors. Zerwekh believes that artificial nutrition and hydration may serve no purpose in hospice patients, and if multisystem failure is present, may contribute to needless and avoidable suffering.

Zerwekh (22) mentions that dry mouth is the main problem that dehydration may cause in the dying patient. Dry mouth is common, and can lead to mucosal cracking and inflammation, or to bacterial, viral, or monilial infections in the mouth. Schmitz and O'Brien (8) mention that dehydration can lead to electrolyte imbalances, which can result in such symptoms as twitching, muscle spasms, or altered levels of consciousness. However, a study by Oliver (24) of 22 hospice patients who did not receive artificial nutrition and hydration, showed that 12 had essentially normal electrolyte levels, 5 were uremic, and 5 were both uremic and hypercalcemic. However, all 22 patients died peacefully. Similarly, Waller et al (25) studied 68 palliative care patients, in which 13 received intravenous fluid infusion (IFI), and the remainder did not. It was found that most of the patients had severe dehydration and electrolyte imbalance, including those who received IFI, and that the level of consciousness did not correlate with the use or non-use of IFI.
Zerwekh (22) mentions that IV fluids administered to some dying patients can be advantageous. Correction of the patient's fluid and electrolyte imbalance may result in increased alertness and an overall sense of well-being; less nausea; and correction of cardiac arrhythmias. However, she emphasizes that the IV fluids may seem to prolong life for a brief time, but the patient will soon die from the underlying disease. Zerwekh concludes that two questions must be asked before administering IV fluids to the dying patient. First, are the IV fluids prolonging the patient's discomfort and suffering? And, second, are the IV fluids relieving any symptoms?

Research Studies

Research about terminal starvation and dehydration falls into three categories: qualitative research consisting of surveys and questionnaires with hospice nurses and doctors; research with palliative care patients; and case studies of dying patients.

Six studies with nurses and doctors who care for dying patients were found in the literature. Michaelsson et al (26) interviewed 60 ward sisters (head nurses) and practical nurses who attend geriatric patients about their methods of assessing thirst among severely demented terminal patients. Most interviewees agree that it is difficult to assess thirst when the patient herself cannot express her feelings. Assessment criteria were classified into six categories: a priori opinion; intuition; identification with the patient; observation of the amounts of fluids received; analysis of the patient's behavior; and observation of the state of hydration. The authors conclude that all six methods of thirst assessment are problematic.
In a part of this same research project, Michaelsson et al (27) evaluated the observations and nursing activities of the 60 ward sisters and nurses from 30 wards with regard to practices to nourish and rehydrate the same patients. For some patients, as dementia worsens, it becomes impossible to nourish them by spoon-feeding, so tube feeding and subcutaneous or intravenous infusions may be used. Of 30 wards, nurses of 25 wards said they occasionally give IV infusions to end-stage patients. In 12 of these wards, IV's were preferred to subcutaneous infusions. The nurses from 20 wards said that they occasionally give subcutaneous infusions. In four wards, IV infusions are used as often as subcutaneous infusions. In 17 of the 25 wards that usually administer infusions, some patients are allowed to die without infusions. For instance, in 5 of the 30 wards, no infusions are given to dying patients with senile dementia. The reasons cited for not giving infusions were because the patient's meaningless suffering is prolonged; relatives wish that infusions not be given; the patient had previously expressed a wish to be allowed to die without infusions; and infusions produce respiratory distress in the dying patient.

Andrews and Levine (28) conducted a study of 95 hospice nurses to determine their perceptions of dehydration in terminal patients. The questionnaire contained ten statements about dehydration to which respondents chose their level of agreement on a five-part Likert scale. Of the nurses surveyed, 71% agree that dehydration reduces the incidence of vomiting; 73% agree that dehydrated patients rarely complain of thirst; 51% report that there is relief from choking and drowning sensations when fluids are discontinued; and 53% agree that dehydration can be beneficial for the dying patient. Also,
85% of respondents disagree with the need for hydration by IV and/or tube feeding when dying dehydrated patients have a dry mouth. Finally, 82% of respondents disagree with the statement that dehydration is painful. The authors conclude that dehydration may contribute to a more comfortable death.

Miller and Albright (2) conducted a survey of 30 hospice nurses to determine the importance of nutrition and dehydration among clinical nursing staff. Of the nurses who completed the questionnaire, 77% cite poor appetite as the main reason why terminal patients do not eat; 95% feel that aggressive nutrition support would do more harm than good; 72% feel that malnutrition did not seem painful; and 77% believe that patients dying with hydration did not suffer much. Weight loss was much more of a concern to family members (77%) than to patients (26%), consistent with the notion of the symbolic value of food.

Jansson and Norberg (29) interviewed 20 female nurses who work with cancer patients about their views of artificial feeding of terminal cancer patients. A structured, taped interview lasting for about one hour was used. The interviewer presented a hypothetical situation of a terminally ill, mentally alert, old female cancer patient who refused food. The interview was assessed to determine whether or not the nurses would feed this patient, and under what circumstances they would change their minds. All 20 subjects chose not to feed the patient, stressing that they would not use either force or violence. They also stressed that their decision very much depended upon the actual situation at hand. All described how they would try to give the patient different encouraging reasons to eat, and would offer food at every meal. Several conditions could make the nurse change her
mind about administering artificial feeding: if the medical head gave an order to feed the patient (n = 10); if others at a full staff meeting held the opposite opinion (n = 4); or if the nurse knew that the patient had previously stated that she regarded life as sacred, and that she had been eager to feed a retarded child (n = 33).

Collaud and Rapin (19) surveyed 397 physicians in a variety of specialties to assess their perception of suffering resulting from dehydration. The questionnaire described hypothetical cases of dehydration in an elderly terminal cancer patient in different clinical situations: conscious, demented, and comatose. Seventy-eight percent (78%) consider dryness of the mouth to be the main cause of discomfort in dehydrated patients, followed by thirst (43%), nausea (23%), cramps (12%), and hunger (1%). Forty-two percent (42%) of respondents think that dying patients suffer significantly from dehydration, while 33% think such patients scarcely suffer. Sixty percent (60%) of physicians do not consider the presence of an infusion to be an additional source of discomfort, and patient opinion is considered by 77% to have the most important bearing on the final decision about providing intravenous infusion. In general, physicians in favor of artificial hydration more often consider dehydration to be unpleasant for the patient. The authors conclude that two-thirds of respondents think that artificial hydration is not the most adequate way to manage dehydration in a dying patient.

Three studies of dehydration with terminal patients were found. Dolan (30) describes a small study with hospice patients concerning the need for tracheal suction to remove fluid and lung congestion as a patient nears death. They found that 12 hospice patients, who had renal shutdown 24-48 hours before death, died peacefully, and did
not need suctioning. At the same time, 12 patients who had been hospitalized before death, and who also experienced renal shutdown, needed to be suctioned. The only apparent difference found between the two groups of patients was the use of IV therapy in the hospital group. The author concludes that once kidney function has all but ceased, the body must not be overloaded with IV fluids, or discomfort results for the patient.

Burge (31) studied the distribution of seven commonly cited dehydration symptoms among 52 inpatient palliative care patients and determined the association between amount of fluid intake and severity of symptoms. The subjects rated severity of symptoms, using visual analogue scales, and associations were determined between symptom severity rating and the possible predictor variables: fluid intake, serum sodium, urea, and osmolality. Confounding variables considered were age, oral disease, and mouth care frequency. Mean symptom ratings (range 1-100 mm) are: thirst (54), dry mouth (60), bad taste (47), nausea (24), pleasure to drink (62), fatigue (62), and pain (34). No significant association was found between the symptom ratings and the predictor or confounding variables, and there was no demonstrable association between severity of thirst and fluid intake, the key concern of clinicians and families.

McCann et al (16) monitored 32 inpatient palliative care patients to determine the frequency of symptoms of hunger and thirst, and to evaluate if limiting food and fluids to only that requested has an adverse effect on the quality of remaining life. Most patients were older than 60 years of age, and had diagnoses of cancer or stroke. Patients were offered whatever food they felt they could eat, and were fed, if necessary, but never forced.
Patients had to be able to communicate needs consistently to caregivers to enable assessment of discomfort from hunger or thirst. The patients were asked several times per day about sensations of hunger, thirst, and dry mouth. Thirst and dry mouth were both considered to be thirst, and both hunger and thirst were recorded as present or absent. Also, consumption of food and fluids and their effect on symptoms of hunger, thirst, and overall comfort were recorded.

Results indicated that hunger and thirst were absent entirely, or, when present, occurred as one of two major patterns, present either throughout the entire admission or only initially within the first 25% of total days. Twenty patients (63%) experienced no hunger. Eighteen of these 20 patients requested small amounts of liquid and solids, one person drank only small sips of liquid, and one person ate or drank nothing. Eleven patients (34%) had hunger present initially, but eventually lost their appetite. Eight of these patients drank and ate small amounts of liquid and solids, and three patients drank only small amounts of liquid. One patient's appetite was present until death and was satisfied with normal amounts of liquid and solids initially, and small amounts of food the last two days before his death.

Twenty-one patients (66%) experienced thirst or dry mouth only initially in their stay (9 patients) or until death (12 patients). The symptoms were relieved with foods, fluids, ice chips, and mouth care. Eleven patients (34%) did not experience thirst or dry mouth during their stay and drank and ate mostly small amounts of liquid and solids (8 patients) or reduced liquids (3 patients). Only one patient had an intake of food and fluids calculated to be greater than 75% of his daily requirement.
All of the patients died in the comfort care unit. Twenty-seven patients (84%) were considered to have been comfortable during their stay and subsequent death, and 4 patients (13%) were thought to have experienced some discomfort during their stay. An 83 year-old man with prostate cancer and a length of stay of 104 days initially experienced hunger and thirst, relieved with small amounts of nourishment, but became more anorectic and stopped eating and drinking two weeks before his death. The authors conclude that patients with terminal illness can experience comfort despite minimal or no intake of food or fluids. Lack of food and fluids did not cause them suffering, as long as mouth care was provided, and thirst was alleviated with sips of water. In nine instances, patients experienced abdominal discomfort and nausea when they ate to please their families.

Four articles containing case studies were found in the literature. Yan and Bruera (32) describe three cases in which patients were managed with a combination of oral and subcutaneous hydration in the palliative care unit. Patient 1 (female, 60 years old) was in good pain and overall symptom control, and in excellent cognitive status. She could not maintain adequate oral hydration, so hypodermoclysis was used for four days until her gastrointestinal motility problem was solved, and oral intake improved. The patient lived for another three months before dying peacefully. Patient 2 (male, 80 years old) was admitted with moderate dehydration, and appeared to be confused, agitated, and hallucinating. Hypodermoclysis was used for several days twice during the patient's stay to improve his mental status when oral intake decreased, and was removed when oral intake improved. On day 24, hypodermoclysis was again initiated
and the patient died 12 days later. Patient 3 (female, 69 years old) was admitted in good pain control, but had mild dehydration and very poor oral intake. Dehydration was treated with hypodermoclysis until day 24. Her condition deteriorated, and parenteral hydration (IV and nasogastric tube) was used postoperatively from days 65 to 80. Parenteral hydration was discontinued when oral intake improved. She lived for another four months with excellent symptom control. The authors state that these three patients represent carefully selected cases in which rehydration prevented additional distress. In each case, the patient was in good symptom control, and the maintenance of hydration allowed the use of other therapeutic interventions, such as anti-nauseants, laxatives, enemas, antibiotics, and palliative surgery. Yan and Bruera (32) emphasize that a general policy of administering parenteral hydration to all terminal cancer patients may prove to be wrong, and each case must be assessed carefully.

Printz (33) mentions three case studies of terminal patients who died without medical hydration. The first patient (female, 86 years old) suffered from emphysema, recurrent bronchitis, chronic renal failure, and Alzheimer's dementia. She was admitted to the hospital with shortness of breath, received medications, but began refusing to eat and drink. Her family rejected any further medical interventions, took her home, and after eight days, she died peacefully. During her time at home, she did not appear to be in discomfort, and needed no pain medications. Patient 2 (female, 88 years old) suffered from mild dementia, depression, and osteoarthritis. She fell and fractured a hip, suffered a massive stroke in the hospital, and her prognosis was grim. She was transferred to a
nursing home, where she was spoon-fed for several weeks, until she refused to eat or drink. She soon became comatose, and died 20 days after transfer. During that time, she needed no pain medications, and appeared to be comfortable. Patient 3 (male, 40 years old) had cancer with metastases, and suffered from anemia which required transfusions. He was admitted to the hospital for seizures, went into a coma, and was placed on a respirator and IV fluids. After 24 hours, his coma lightened, he was weaned from the respirator, his IV was removed, and he was transferred to comfort care. For three days, he received seizure medications, oxygen, and spoon feedings as tolerated. He remained in a stuporous state, did not require pain medication, and did not appear to be in discomfort. On the fourth day, he died. Printz concludes from these three cases that, although medical hydration would probably have prolonged the lives of these three patients, it would not have added to their comfort. In her experience, dying patients who are medically hydrated undergo a prolonged, painful dying process. In contrast, dying patients without medical hydration die peacefully and more comfortably, 3 to 10 days after the last intake of fluid.

Andrews et al (34) present three case reports of hospice patients who did not receive artificial hydration during the dying process. Patient 1 (male, 64 years old) had cancer of the neck, larynx, and tongue, with massive facial and neck deformity, facial edema, and a continuous flow of secretions from the mouth and tracheostomy site. On admission to hospice, he was alert, in severe pain, and fed himself through a gastric tube which had been inserted previously. Eighteen days after admission, he decided to stop feeding himself. For the next 27 days, he received no
food or fluids; his appearance improved remarkably; his
secretions decreased; and his breathing improved. His pain
was managed, he grew weaker and less responsive, and died
quietly with no signs of discomfort. Patient 2 (male, 77
years old) was admitted to the hospital with pneumonia
secondary to lung cancer. He was lethargic but oriented,
and under constant physical restraint. Ultimately, he
required IV furosemide, a diuretic, because of fluid
overload, and he became less alert, more confused, and
agitated. He was transferred to the hospice unit, and all
treatment, including nasogastric (NG) tube feeding, was
discontinued. Within 24 hours after artificial fluids were
withdrawn, he became alert and responsive; was less
congested; was fully-oriented; and said he felt in control
of his life without the restraints, oxygen, NG tube, and IV
line. On day 3, he declined, and died two days later with
no signs of discomfort. Patient 3 (male, 75 years old) had
lung cancer with metastases and was admitted to the
hospital because of weakness, respiratory distress, and
severe, generalized body pain. Among the treatments
administered were IV fluids and total parenteral nutrition
(TPN). The patient's family transferred the patient to
hospice, and the TPN was discontinued. Respiratory
congestion decreased, and the patient became alert. As his
condition gradually deteriorated, he remained responsive
and able to interact. He died quietly with no signs of
discomfort. The authors conclude that, while artificial
nutrition and hydration may play an important role in
preserving life and facilitating patient recovery, in
terminally ill patients, discontinuing such treatment is
more beneficial.

Watts and Cassel (35) describe one case study in
detail, and provide an analysis of the ethical issues
involved in the patient's situation and in the decisions made for his care. Mr. V, 89 years old, had lived in a nursing home for two and one half years because of confusion, incontinence, and dangerous behavior. He was admitted to the hospital in a stuporous and unresponsive condition, and was considered to have a poor functional outcome, but a small possibility of fair recovery. It was decided to use IV fluids to prevent dehydration. He ate small amounts of food with much assistance, and his fluid intake was inadequate. On day 10, a nasogastric (NG) tube was passed and IV saline was continued. Over the next few days, he pulled out his NG tube twice, and would spit out food when the nurses attempted to feed him. On day 17, he pulled out the IV and became progressively malnourished.

The interdisciplinary team and the patient's family decided that his refusal of feeding was voluntary and an expression of his wish to die. A two week trial of peripheral IV hyperalimentation was tried. The patient remained stable, but his mental status did not improve. After two weeks, IV therapy was stopped and Mr. V became more responsive. His oral intake remained low, comfort measures were taken, and he died ten days after IV feeding was stopped.

**Recommendations**

Several authors provide guidelines for treating the symptoms of starvation and dehydration in terminal patients without resorting to artificial means. Zerwekh (22) suggests good mouth care: have the patient rinse his mouth often; remove any debris in the patient's mouth; brush the patient's tongue, gums, and teeth with a soft toothbrush; offer ice chips or small sips of favorite fluids if the
patient is conscious; if the mouth is inflamed, use Benadryl and a topical anesthetic to reduce pain; and cover lips with Chap Stick, vaseline, or other protective coating. Brooker (9) recommends good mouth care; oral intake as tolerated; skin care for dry skin to prevent skin damage; monitoring of temperature, with use of cool wipes, fan, cool drinks, light clothing and bedcovers; monitoring for weakness, dizziness, or fainting; minimizing the amounts of medications prescribed and monitoring for increased side effects; and monitoring levels of anxiety and ability to function adequately.

Brown and Chekryn (6) emphasize identifying and reversing factors which contribute to starvation and dehydration, such as nausea and vomiting or painful mouth lesions; and implementing nursing strategies to reduce possible discomfort from dehydration, such as using mouth care. Holden (35) recommends aggressive medical management of nausea, vomiting, and diarrhea; dietary efforts to enhance oral fluid intake according to patient tolerance; use of lubricants, such as artificial tears and saliva; meticulous and frequent mouth care; ice chips and sips of fluid if the patient can swallow; and tranquilizing medications to relieve restlessness and muscular twitching.
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KEY ISSUES DISCUSSED IN PART III:

- Starvation in normal humans results in many physical, functional, and psychologic symptoms. In total starvation, the sensation of hunger may disappear in a matter of days.

- Dehydration in normal humans can also result in physical, functional, and psychologic symptoms. Dehydration is a common problem among older adults.

- Factors which may increase the risk of dehydration in older adults are: requirements for tube feeding or assistance with feeding; being bedfast; having more than four chronic diseases; taking more than four medications; using laxatives; and presence of infection.

- The medical consequences of starvation in a severely ill or dying person are difficult to judge. It has not been proven that nutrition support will benefit the terminal patient.

- Providing food and fluids is an extremely symbolic act and represents care and compassion for another person.

- Many hospice workers believe that as a patient dies, it is normal to stop eating and drinking. In fact, terminal starvation and dehydration may be palliative.

- In the hospital setting, it is likely that a dying person will receive IV hydration as routine care.
PART IV: ARTIFICIAL NUTRITION AND HYDRATION

Introduction

The preferred way to meet a patient's nutrition needs, even one who is terminally ill, is orally (1,2). Tube feedings should never be initiated when oral feeding may still be an option (3). For patients who cannot maintain optimal nutrition or hydration orally, medical techniques may be necessary (4,5). Artificial means of nutrition and hydration may be necessary for a short time, e.g., following surgery when a patient is temporarily unable to eat (4). Up to seven days of relative starvation is well tolerated, and is not thought to impair recovery in the initially well-nourished patient (5). Long-term artificial feeding may be necessary for conditions such as strokes, prematurity birth, severe neuromuscular diseases, severe dementia or psychiatric illness, anorexia associated with cancer or its treatment, and malabsorption syndromes (4).

This section will review the medical means of nutrition intervention which are available, including enteral and parenteral methods, their indications and contraindications for use, and potential complications. It will also cover the psychosocial factors associated with artificial feeding methods. Chapter 8 will discuss the ethical considerations of providing artificial feeding and hydration to terminal patients.

As stated in the previous section, many health care providers who work with hospice and palliative care patients do not believe that artificial nutrition and hydration should be routinely used for such patients. However, hospice programs may find it appropriate to provide enteral or parenteral support to some patients.
McCamish and Crocker (6) mention the following examples of hospice patients for whom artificial feeding methods may be appropriate: (1) patients who have a feeding tube or line in place and want it to continue to be used; (2) patients for whom an untimely and uncomfortable death may occur without artificial nutrition or hydration; (3) patients for whom it is important to prolong life so that an important event can occur before the patient dies; (4) patients for whom there is a threat of legal action if the tube or line is not placed or used when the patient's wishes are not known; and, (5) patients for whom the tube or line is a source of control or denial.

Chapter 7: Enteral and Parenteral Feeding Methods

Enteral Feeding Methods

The first basic type of medical intervention that provides food and fluids to the patient who cannot eat by mouth involves a tube which is inserted into a functioning gastrointestinal (GI) tract (6-9). Enteral feeding is the preferred route of artificial nutrition administration, and can be classified into two general categories based upon the route of formula delivery: nasoenteric and tube enterostomy (3,9). Enteral feeding promotes more efficient utilization of nutrients and preserves the intestinal integrity (10). The liquids used can be specially prepared nutrition formulas or a blenderized version of an ordinary diet (7).

Nasoenteric tubes can be inserted through the nose into the stomach (nasogastric), duodenum (nasoduodenal), or jejunum (nasojunal) (5). Nasoenteric tube feeding is the most frequently used route for artificial feeding and is
the preferred method for patients in need of short-term feeding for less than four weeks (9,11).

Feeding by tube enterostomy is used in patients needing long-term feeding for more than four weeks (9,11). Among the types of surgical access are cervical pharyngostomy, esophagostomy, gastrostomy, and jejunostomy, involving surgical placement of the feeding tube in the pharynx, esophagus, stomach, or jejunum (8,9). Gastrostomy is the most common method of feeding by tube enterostomy (9). The newest advance in gastrostomies is the percutaneous endoscopic gastrostomy (PEG), which does not require a formal surgical procedure. This technique is especially useful in elderly patients and others who are poor surgical risks (4,8,9). Figure 6 illustrates the placement of several types of enteral feeding tubes (2).

The first requirement for enteral tube feeding is that the patient have a functioning GI tract (1,4,11). Several authors (1,2,5,11,12) provide some general guidelines about when enteral nutrition may be appropriate. Tube feeding is helpful when the patient has dysphagia or impaired swallowing for some reason, including the presence of central nervous system disorders, coma, stupor, unconsciousness, stroke, dementia, multiple sclerosis, Parkinson's disease, amyotrophic lateral sclerosis (ALS), or because of head and neck surgery. It may also be appropriate for patients who cannot eat by mouth because of anorexia nervosa, depression, head and neck surgery, esophageal obstruction, or cerebral or oropharyngeal cancer. Other indications for use are: conditions which impair digestion or absorption; hypermetabolism due to cancer, surgery, or burns; or multi-organ failure.

Other authors (1,5) mention contraindications for enteral feedings. Tube feedings should not be given to
Figure 6: Routes of enteral hyperalimentation administration (2)
patients with the following problems: severe malabsorption; intestinal obstruction; peritonitis; GI hemorrhage; intractible vomiting or diarrhea; or a high risk of aspiration.

Enteral tube feedings can result in complications related to the mechanisms of the tube feeding process; the patient's GI function or metabolic processes; psychosocial factors; or infection (5). The most common problem is aspiration or reflux of stomach contents, which is more prevalent among elderly patients and others with neurologic problems, swallowing problems, or who are comatose (3,9,13). Several authors (3-5,12) mention some common problems which can occur in the tube fed patient: nausea, vomiting, diarrhea, constipation, or cramping; dehydration or edema; obstruction of the feeding tube; tube migration or displacement; hyponatremia or hyperglycemia; upper GI bleeding from stress ulceration, gastritis, or reflux esophagitis; and irritation of mucosal surfaces. Stoma problems may occur, such as leakage of gastric contents, causing skin maceration and ongoing nutrient losses. Sometimes, patients are restrained to prevent self-extubation. Restrained patients are likely to be depressed, angry, or agitated over being restrained, and may develop pneumonia and bedsores because of lack of activity and remaining in fixed positions.

Campbell-Taylor and Fisher (13) take a position against tube feedings in a specific group of elderly patients who are in the terminal stage of a progressive, neurologic disease. Such patients are usually noncommunicative because of speech and/or language difficulties; spend most or all of the time in a recumbent position; usually have dysphagia; and have been suspected clinically or observed to be aspirating liquids and pureed
foods. Any type of tube feeding poses the significant hazard of aspiration pneumonia. Tube feedings are also contraindicated for these patients since they may also exhibit delayed gastric emptying; reduced esophageal peristalsis; and reduced competence of upper and lower esophageal sphincters.

In one recent study, Ciocon et al (14) prospectively studied 70 tube-fed patients in a skilled nursing facility, aged 65 to 95 years. The authors' purpose was to describe their experience with various methods of enteral nutrition in geriatric patients, and report the indications for, and the clinical benefits and complications of, tube alimentation. Indications for alimentation were: refusal to swallow (n = 35, 50%); dysphagia without obstruction (n = 33, 47%); and esophageal obstruction (n = 2, 3%). During the eleven month study period, tube feedings were initiated and observed in 59 patients, and observed in 11 additional patients who had been receiving tube feedings for as long as 7 years before the study.

With nasogastric tube feeding, the early observed problems were agitation and self-extubation; aspiration pneumonia; difficulty in insertion; and kinking, misplacement, and clogging of the tube. Except for misplacement, late complications involved the same problems, but clogging was considerably more common and agitation less common. Early complications of gastrostomy tubes (G-tube) and jejunostomy tubes (J-tube) were agitation and self-extubation; pneumonia; misplacement; difficulty in insertion; clogging; infection at the insertion site; leakage around the tube; and one incident each of pain at the site and peritonitis. On tube feeding, most patients maintained a stable weight for 2 to 6 months, and weight gain occurred in no more than 6% of patients at
any time in the study period. Twenty-eight (40%) of the 70 patients died during the study period, probably related to aspiration. The authors conclude that tube feeding in elderly patients can be continued for long periods, but is associated with a high frequency of complications.

Wolfsen et al (15) retrospectively studied the records of 191 patients, mean age of 66 years, who had percutaneous endoscopic gastrostomy and jejunostomy (PEG/J) tubes placed. The authors' purpose was to evaluate long-term patient survival and incidence of subsequent PEG/J tube removal following recovery of oral intake. Diagnoses of the patients were: cancer (n = 68, 36%); benign mechanical obstruction or disordered mechanisms of swallowing (n = 102, 53%); and inability to maintain enteral nutrition (n = 21, 11%). Total mortality was 60% (n = 115), with the median time of expiration at 164 days after the procedure. Forty patients (21%) died within 30 days of tube placement. PEG/J tubes were removed in 41 patients (21%) after recovery of adequate, safe, and reliable oral intake. The authors conclude that the high cumulative mortality rates and low incidence of PEG/J tube removal following recovery of oral intake suggest that long-term feeding or subsequent tube removal may not be realistic goals for some patients. In their experience, PEG/J placement appears to facilitate patient discharge from the hospital to home care or step-down care facilities. Thus, potential PEG/J patients must be evaluated carefully, since benefits may be limited in patients with projected early mortality or who are unlikely to be discharged from the hospital.
**Parenteral Feeding Methods**

The second basic type of medical procedure to provide food and fluids to a patient who cannot eat by mouth involves insertion of nutrients directly into the circulatory system (5). Parenteral nutrition refers to the provision of nutrients by any route that does not involve the GI tract, and is used when the GI tract is inaccessible, not functioning, or is partially functioning but incapable of absorbing sufficient nutrients to meet the patient's metabolic requirements (5,9). Nutrients are administered intravenously either by central or by peripheral vein (1). Since the GI tract, with its digestive function, is bypassed in parenteral nutrition, the nutrients must be provided in a predigested state (5).

There are three major types of parenteral nutrition (2). Total parenteral nutrition (TPN) is the administration of amino acids and hypertonic dextrose in adequate concentrations to meet the total protein and energy needs of the patient. Adjuvant lipid therapy is also used two to five times per week to replace the essential fatty acids. Parenteral nutrition (PN) is the administration of amino acids to provide protein and hypertonic dextrose for energy. Fat is not administered with this form of therapy. In both TPN and PN, the hypertonic dextrose solution dictates the need to administer this solution via a catheter surgically placed in a central vein, usually the superior vena cava. Figure 7 illustrates the placement of such feeding tubes (5).

The third type of parenteral nutrition is peripheral hyperalimentation, which is the administration of amino acids, with or without concomitant administration of isotonic dextrose, via a peripheral vein. Fat emulsions are also administered to provide an adequate energy source.
Figure 7: Central parenteral nutrition as administered into large veins: superior vena cava and subclavian (5)
Peripheral venous hyperalimentation is suitable for short-term use of from 7 to 10 days (5).

A fourth method of parenteral feeding is the subcutaneous fluid infusion, or hypodermoclysis, in which a needle is inserted into the subcutaneous tissues, and fluids are dripped into the tissue spaces, from which they are gradually absorbed (4,16). This method is sometimes used for hydrating terminally ill patients (16). Ashby et al (16) mention that it may be appropriate to use hypodermoclysis temporarily in palliative care patients who feel dry, despite frequent drinks and mouth care; who have nausea, vomiting, or infection with fever and dehydration; or who have biochemical disturbances, such as hypercalcemia.

The primary indication for use of any parenteral method of feeding is a dysfunctional GI tract (1,9,17). If the gut works, oral or enteral feeding is appropriate (1). Several authors (1,5,11,17) mention some general conditions for which parenteral feeding may be appropriate: when the GI tract is abnormal, unavailable, or obstructed; pre- or post-surgically; if the abdomen is injured; and for inflammatory bowel disease, short bowel syndrome, sepsis, peritonitis, pancreatitis, renal failure, Crohn's disease, or reversible liver failure. Other appropriate conditions may be if intractible nausea and vomiting are present; if the patient is extremely weak; if malabsorption or malignancy is present; if the patient is anorectic or unwilling to eat because of cancer, chemotherapy, radiotherapy, depression, or anorexia nervosa; if the patient suffers from recurrent aspiration pneumonia while receiving tube feedings; or if a patient cannot be fed orally or enterally for at least 7 to 10 days.
Complications are possible with different types of parenteral feeding. Insertion of a central venous catheter can result in injury to the pleural cavity; laceration of the vasculature; injury to the nerves at the insertion site; or laceration of a lymphatic duct (2). Other serious complications of PN or TPN can include: hyperglycemia or hypoglycemia; catheter sepsis; development of fatty infiltration of the liver; respiratory failure from infusion of excess glucose; and fluid and electrolyte imbalances (1,2,5,9). In addition, peripheral venous alimentation can result in local inflammation, thrombophlebitis, and infection of the insertion site (18). Problems with hypodermoclysis include: fluid overload and pulmonary edema; infection of the site; pain; hemorrhaging and bruising if there are platelet or coagulation problems; and the remote possibility of accidentally entering a large vessel (16).

Use of parenteral feeding in elderly patients presents special complications. Many older patients have occult or overt diabetes mellitus, and the carbohydrate load associated with elemental enteral and parenteral nutrition may cause problems with glucose regulation (9). TPN therapy for the older patient must consider age-related changes in body composition; total body water; lean body mass; possible impairments in renal function; major functional changes from chronic illnesses, such as cardiovascular or renal disease; impaired ability to withstand metabolic stress; and possible reduced immuno-competence.
Psychosocial Aspects

Artificial nutrition can be a life-saving intervention providing significant benefit (20,21). However, Srp et al (21) explain how using artificial nutrition support is not as innocuous as many health care providers think, and both patients and families may face significant psychosocial problems. Patients requiring nutrition support may experience many of the same problems as other patients, such as loss of control, separation from family and friends, fear of the unknown, and anxiety. Nutrition support patients are faced with an additional change which affects their ability to meet a basic biological need: eating. By the time nutrition support becomes necessary, the patient is often weak and debilitated as a result of inadequate nutrition over a prolonged period of time, and is often depressed because of his hospital stay, prolonged illness, or complications which are present.

Mealtime in a family setting involves socialization in addition to nourishment (22). When a family member requires artificial feeding, the family must readjust to this new source of stress (21). Family members may feel uncomfortable cooking and eating foods that the patient finds difficult to digest or cannot eat (21). However, other family members should not feel guilty about eating normally, and emphasis should be placed on conversation and togetherness, instead of on food (22).

Many patients dislike transnasal tubes because of the comfort factor or because of body image problems. Patients may feel self-conscious about their appearance, which hinders their ability to maintain normal social relations (21,22). Poor body image may also interfere with sexual function, placing additional stress on family relationships (21,22). Patients with ostomy tubes are usually in a weak
condition, may be unable to do even minimal activities of daily living, and often feel overwhelmed by daily self-care needs, such as care of ostomies (21). Emaciated patients may see themselves as unattractive and have very poor body image (21).

Padilla et al (20,23,24) report that common complaints of tube fed patients involve: being deprived of favorite foods; not tasting, chewing, and swallowing foods or drinking liquids; exposure to forbidden foods; and unsatisfied appetite for certain foods. In addition, intubation can cause distress from soreness of the nose and throat; runny nose; having a tube in the nose; and limited mobility. Rains (25) studied ten patients on long-term home enteral feeding who were older than 50 years of age. The most common psychosensory complaints focused on the deprivation of favorite foods. Also, when gastrointestinal symptoms, such as flatus, diarrhea, constipation, nausea, or fullness were controlled, patients were able to resume most of their usual activities.

Gulledge et al (26) studied 50 patients on home parenteral nutrition and identified feelings of depression, grief, organic brain syndrome, drug dependency, and body image changes. Price and Levine (27) interviewed 19 patients in the early stages of receiving TPN. Most patients experienced moderate to severe depression, and were concerned with altered body image, loss of the ability to eat, and unreliable functioning of the feeding apparatus. Ladefoged (28) studied 13 patients receiving long-term parenteral nutrition, and all complained of some physical distress, including weakness. Major adjustment problems related to the loss of normal oral eating function, and five patients reported no sexual activity. Perl et al (29) studied ten patients on home PN for at
least six months. Common psychological problems were depression, crying, insomnia, and feelings of hopelessness; and feelings of being "weird" because of the indwelling catheter. Generally, sexual function decreased, and finances were frequently jeopardized. Malcolm et al (30) studied long-term TPN in 59 patients. These subjects reported depression, concern over changes in body image, distress over the inability to eat normally, fear of malfunctioning of the apparatus, feelings of dependency, and some loss of sexual activity.
REFERENCES


Chapter 8: Ethical Considerations

The Need for Ethical Analysis

Modern medical technology, such as artificial feeding, mechanical ventilation, and kidney dialysis, can totally support patients, and can prolong life indefinitely (1-4). For any condition, some intervention exists that might delay death (5). Even if such technology is ultimately unable to conquer death, it can determine the conditions and time of its occurrence (4). The existence of the technology increasingly forces the decision whether to use a given intervention simply because it is available (5). Ethical analysis can provide a framework for making appropriate treatment decisions.

Ethical theories and reasoning do not solve ethical problems, but rather suggest ways of structuring and clarifying them (6). There are usually no absolutely right or wrong solutions to ethical dilemmas, and they are not resolved by technical data (6,7). The crucial problem in ethics is not identification of values; a problem arises only when one value comes into conflict with another (8). Ethics as a discipline allows us to analyze competing values in a rational manner, assessing and determining the relative weight to be assigned to each moral value compared to all others (8-10). Brody and Noel (11) describe the process of arriving at an appropriate ethical decision as conducting a special "productive moral conversation" among all involved persons to clarify all the ethical issues, and consider and respect all relevant viewpoints.

Annas (2) reminds us that people, not technologies, have rights. No medical treatment, including artificial nutrition and hydration, is always absolutely morally obligatory; whether it is morally obligatory depends on the
patient's condition, interests, and wishes (12). Various medical procedures can be withdrawn in order to ease the process of dying for the terminal patient at the end of life (13). Ethical decisions about withdrawing life-sustaining technologies must also be made for patients who are: comatose; non-comatose but in the last stages of dying from some illness; senile or retarded with chronic degenerative diseases; or newborn infants with severe handicaps (13). The health care provider has the obligation to care for the patient, but the content of that obligation of care should be shaped by the patient's needs and preferences (12). The goals of any technology should be to preserve life and relieve suffering, but the health care provider is not free to do everything to achieve these goals (9).

This chapter will review the four basic principles of biomedical ethics, and some of the ethical considerations about providing artificial feeding which are based upon these principles. Although much has been written about religious and legal issues related to the artificial feeding of certain patients, these considerations will not be reviewed in this dissertation.

The Principles of Biomedical Ethics

Ethics is a generic term for several ways of examining the moral life (14). Ethical theory is the process by which we organize and examine complex information and competing values and interests, in order to formulate and justify a particular ethical decision (15). An ethical theory provides a common means and a framework of principles used to approach various problems (14,15). Some ethical theories, which will not be described here,
include: utilitarianism, consequentialism, deontology, rules ethics, rights ethics, and intuitionism (14,15). The four basic ethical principles of autonomy, nonmaleficence, beneficence, and justice can be examined in terms of various ethical theories.

Autonomy refers to a set of diverse notions, including: self-governance, liberty rights, privacy, individual choice, liberty to follow one's will, causing one's own behavior, and being one's own person. The core idea of personal autonomy is personal rule of the self while remaining free from both controlling interferences by others and personal limitations, such as inadequate understanding, that prevent meaningful choice (16). Autonomy involves two elements: the capacity to deliberate about a plan of action, and the capacity to put one's plan into action (15). The principle of autonomy includes respecting a person's autonomy by recognizing her capabilities and perspective, including her right to hold views, make choices, and take actions based on personal values and beliefs. A person must be treated so as to allow or enable him to act autonomously (16). Some biomedical notions which are derived from the principle of autonomy are: informed consent; decisionmaking capacity or competence to consent; disclosure of information; ability to comprehend or understand; voluntariness; truthfulness; confidentiality; privacy; and paternalism (15,16).

The second principle of nonmaleficence involves an obligation not to inflict harm on another person, intentionally or directly. Harm can be physical or mental, but can also include setbacks to reputation, property, privacy, or liberty (15,17). Generally, in biomedical ethics, harm refers to physical harms of pain, disability, and death, especially intending, causing, and permitting
death and the risks of death. Duties of nonmaleficence include not imposing risks of harms as well as not inflicting actual harms (17). Also, when some harm or risk of harm appears to be necessary, then we need to be accountable (15). Some biomedical issues which arise from the principle of nonmaleficence are: the distinction between killing and letting die; withholding and withdrawing life-prolonging treatments; optional and obligatory means of treatment; quality of life considerations; standards for proxy decisionmaking; and assessment of benefits vs burdens of a treatment (17). Nonmaleficence can be summed up as the principle which requires that, if we cannot benefit someone, then at least we should do that person no harm (15).

The third principle, which is the positive side of nonmaleficence, is beneficence, which requires that we help others further their interests when we can do this without risk to ourselves (15). Beauchamp and Childress (18) explain the principle of beneficence in relation to health care. Beneficence requires the provision of benefits, including the prevention and removal of harm and the promotion of welfare, and asserts an obligation to help others further their important and legitimate interests. Beneficence also includes the obligation to balance possible benefits against the possible harms of an action. The belief that there is an obligation to provide benefits and promote the welfare of patients, not merely to avoid harm, is the goal of health care. Clinical therapies are aimed at the promotion of health or the prevention of disease and injury. The positive benefit that health care providers are obligated to seek is the promotion of health, as defined in part by the patient's own wishes. Health care aims at the restoration of the patient's health, if
there is reasonable hope of cure, but often involves modes of care which cannot cure. In the latter case, ethical decisionmaking often becomes necessary. The harms to be prevented, removed, or minimized include pain, suffering, disability, and death from injury and disease.

Justice is the fourth ethical principle, and deals with the allocation of resources, and the distribution of benefits and burdens, and of goods and services, according to a just standard (15). In biomedical ethics, the term "just" refers to what is generally justified or morally right (19). One acts justly toward a person when that person has been given what he deserves, is entitled to, and is due. An injustice involves a wrong where one has been denied that to which he is entitled (19). Included in the principle of justice are such biomedical issues as: fair opportunity to medical care; the right to a decent minimum of health care; allocation of health care resources; and rationing health care.

The four preceding ethical principles apply to decisionmaking about providing medical treatments including artificial nutrition and hydration, to patients. The next section discusses ethical decisionmaking in general. The subsequent sections review some of the major ethical considerations about artificial feeding which incorporate the above principles, and are used for formulating appropriate treatment decisions for certain patients. These considerations are closely interrelated, and are meant to facilitate the identification and clarification of issues, and the consideration of relevant ethical viewpoints. The considerations chosen for discussion are those most often mentioned in the biomedical ethical literature.
Ethical Decisionmaking

The Hastings Center has published a set of guidelines (20) for making treatment decisions, which are generally in agreement with the views of most ethicists and physicians. As previously mentioned, one of the basic principles of biomedical ethics is autonomy or self-determination, which is the right of an individual to decide her own destiny by accepting or rejecting any medical treatment which is offered (15,16). The Hastings Center emphasizes that any decision about whether to use a life-sustaining treatment, including artificial feeding, requires a decision by the patient who has decisionmaking capacity. Generally, the physician or other responsible health care professional and patient, perhaps with involved family members, consult together; the professional offers recommendations, and the patient uses his own values in making decisions.

Reevaluation of a patient's decisionmaking capacity should be ongoing, with a fuller reevaluation whenever new decisions must be made or the patient's situation changes. The Hastings Center defines a patient as having the capacity to make treatment decisions when she can understand the relevant information, reflect on it in accordance with her values, and communicate with caregivers. A patient need not have decisionmaking capacity for all purposes in order to have the capacity to make one treatment choice but not another. Patients should be presumed competent to make medical decisions until proved otherwise (20,21). It should be recognized that not all elderly patients who have cognitive deficits are demented, and not all cognitively impaired or demented patients are necessarily incompetent to make treatment decisions (22).

When the patient is unable to make treatment
decisions, a surrogate decides. The Hastings Center states that in identifying a surrogate, the health care professional should first honor any surrogate choice the patient has made, whether by advance directive or other written or oral statement. The professional should also recognize the authority of a surrogate appointed by a court. If the patient has made no choice and there is no court-appointed surrogate, then the goal is to find the person who is most involved with the patient and most knowledgeable about the patient's present and past feelings and preferences. If the patient is an adult, the surrogate is usually a spouse, child, parent, sibling, or concerned friend. The guidelines emphasize that someone other than the patient's responsible health care professional should preferably act as surrogate, unless the patient has previously designated the professional to act as surrogate. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (23) clearly states that for several reasons, a family member should usually be designated as surrogate to make treatment decisions for an incapacitated patient in consultation with the physician and other health care professionals. Lynn (24) states that the surrogate who is a close family member, or who directly provides care to the patient, has more authority than does the surrogate who is a stranger. The close surrogate will have to live with the knowledge of the choices made and the motives behind them. In Lynn's opinion, this fact creates a major safeguard for the patient, since family members will be wary of making bad choices or of acting on unsavory motives.

Two sources (20,21) review how surrogates should make treatment decisions. First, the surrogate should try to follow the patient's explicit directives. Where a patient
who had decisionmaking capacity at the time, has left written directions in an advance directive or another form, or clear oral directions, and these directions seem intended to cover the situation presented, the surrogate should follow the directions. In the absence of formal advance directives, surrogate decisionmaking can become complex and troublesome.

The second approach can be made on the basis of "substituted judgment" in which the surrogate should apply what is known about the patient's preferences and values, and should try to choose as the patient would have wanted. The doctrine of substituted judgment ideally implies an intimate sense of the patient's values, a clear knowledge of her wishes, and information concerning how she acted in analogous situations in the past. A substituted judgment cannot be made in instances in which a patient has never expressed a relevant opinion or preference, or if the patient has never been competent.

A third approach to surrogate decisionmaking is the "best interests" standard in which the surrogate chooses as a reasonable person in the patient's circumstances would. If there is not enough known about the patient's directions, preferences, and values to make an individualized decision, the surrogate should choose so as to promote the patient's interests as they would probably be conceived by a reasonable person in the patient's circumstances, selecting from within the range of choices that reasonable people would make. Barondess et al (21) distinguish between a "best interests" standard which requires only the promotion of the patient's well-being, and a "reasonable person" standard, which reflects the perceived desires of an average person in the condition in which the patient is at the time.
The Symbolism of Food and Fluids

Consideration of the morality of withholding food and fluids depends on a philosophical and religious tradition of a general moral duty to feed the hungry and give drink to the thirsty (25). The simple act of offering to ease the hunger and thirst of a dying person is deemed, across time and cultures, to be not only right, but good (26). Callahan (25) states that cutting off food and water goes against our deepest social and moral instincts; thus, the importance of this issue is symbolic. One argument that artificial nutrition and hydration are always obligatory focuses on this symbolic significance: what they symbolize about caregivers and patients, and the relationship between them (12). The act of serving food to a patient carries a highly symbolic value, characterizing the social and community values of caring, and symbolizing the continued care of the patient by the healthcare team. Food also carries with it religious, cultural, and ethnic values that have meaning to patients, families, and healthcare professionals (6).

Consequently, some ethicists believe that we are always obliged to provide nutrition and hydration, even in hopeless cases, because these activities symbolize or express the essence of care and compassion (27). Because human existence is social and communal, we experience a strong sense of responsibility to feed those who cannot feed themselves, and are opposed to starving people to death (13, 26, 28, 29). Breathing and other functions are just as vital, but lack the complexity of the symbolization of eating and drinking (28). Although the family of Karen Anne Quinlan sought the removal of artificial respiration which was prolonging her dying, her father was amazed when asked if he wanted her intravenous feeding stopped. His
reply was, "Oh no, that is her nourishment" (30). McInerney (31) suggests that because the health care professional is not socialized to provide oxygen in the same way as she is into the role of food provider, there is not the same compulsion to supply artificial ventilation as there is to artificially feed, irrespective of their equivalent importance in maintaining life, or their equivalent inappropriateness in certain cases.

Several authors believe that the strong symbolic meaning of food and drink does not justify the artificial feeding of patients under all circumstances. Carson (26) states that feeding is a reciprocal act, and its symbolic significance resides in the mutuality of giving to eat and drink, and of taking food and water. Without this gesture of acceptance, the act of feeding is incomplete, useless, and elective. Yarborough (32) claims that there is a basic obligation to offer food and water, but that patients who must be medically fed are an exception. When providing artificial feeding, the health care professionals are not offering food and water, they are forcing patients to accept nourishment and hydration into their bodies. He concludes that, as there is no absolute legal obligation for a patient to eat, there cannot be an absolute legal obligation for health care professionals to artificially feed all people who do not eat. Offering food and water is humane and respectful; however, it is also humane and respectful to preserve a patient's right to refuse our offer.

Winkler (27) believes that technological means of supplying nutrition and hydration do not always convey the essence of care and compassion. Insisting that always supplying nutrition upholds an important symbolic value is not logical in certain cases, such as when prolonging a
very burdensome process of dying, or in the case of an irreversibly comatose patient. Connelly (28) agrees that artificial feeding can be a form of comfort care, but that its provision to dying patients should be determined on a case-by-case basis. He states that the scientific substitutes provided artificially by tubes reduce food and drink to chemical substances, and reduce the person to a mere organism. When there is little hope for recovery, artificial feeding sustains the body but seems to ignore the person, leading to dehumanization of both patients and their caregivers.

Artificial Feeding as Medical Treatment

Derr (33) provides four reasons why he believes that artificial nutrition and hydration differs from other life-sustaining medical technologies. First, he mentions the finality of not providing food and fluids. A patient may survive denial of surgery or other medical treatment, but can never survive the denial of food and fluids. Second, food and fluids are universal human needs, while medical and surgical therapies are not. Third, denial of food and fluids affects the doctor-patient and institution-patient relationships. He believes that every patient who establishes a professional relationship with a physician or a health care facility knows that her life depends upon the availability and provision of food and fluids, and presumes that her life will be preserved. Fourth, denial of food and fluids affects the integrity of the medical profession, in which the ultimate value is the protection, preservation, and possible improvement of life and health. Denial of food and fluids to patients destroys the medical profession as a profession, and removes the professional's
commitments.

On the other hand, Annas (2) warns against confusing the use of a feeding tube with the provision of nutrition itself. Many ethicists hold that artificial means of providing food and fluids are inherently no different than other medical treatments, and may be removed when deemed useless to patient welfare (27,34,35). Brock (36) argues that forgoing food and fluid does not fall under any special moral prohibitions that would make it morally different than the forgoing of other life-sustaining medical technologies. Holst (34) believes that artificial feeding methods are not common standards of patient care, as are hygiene, safety, and comfort. Rather, feeding devices require the supervision of highly-trained personnel; are invasive to the body; and contain inherent risks and side effects. Thus, they are more similar to other mechanical supports than to eating and drinking orally. In the Cruzan case (37), Justice O'Connor wrote: "Artificial feeding cannot readily be distinguished from other forms of medical treatment".

Ordinary vs Extraordinary Medical Treatment

The rationale underlying the distinction between ordinary and extraordinary means of medical care is the idea that there is a crucial moral difference between intentionally discontinuing ordinary treatment and intentionally discontinuing extraordinary treatment (4). This distinction originated in the field of Catholic moral theology, and was used to distinguish between obligatory and non-obligatory care, based upon the burden that the treatment would place on the patient (38). Ordinary care was obligatory for the patient to accept and others to
provide, and extraordinary care was optional (39).

Kelly (40), a noted Catholic moral theologian, offers the definitions which are often referred to in bioethical literature: "Ordinary means of preserving life are all medicines, treatments, and operations, which offer a reasonable hope of benefit for the patient and which can be obtained and used without excessive expense, pain or other inconvenience... Extraordinary means of preserving life...mean all medicines, treatments, and operations, which cannot be obtained without excessive expense, pain or other inconvenience, or which, if used, would not offer a reasonable hope of benefit."

Pope Pius XII (41), in addressing an international congress of physicians, further clarified this interpretation when he said that all persons have a duty to preserve life and health, and stated: "But normally, one is held to use only ordinary means — according to circumstances of persons, places, times and culture — that is to say, means that do not involve a grave burden for oneself or another. A more strict obligation would be too burdensome for most men and women and would render the attainment of the higher, more important good too difficult...."

More recently, the term "ordinary means" has come to denote medical procedures that are routine, customary, usual, simple, inexpensive, and noninvasive. "Extraordinary means" are understood to be those procedures that are new, experimental, unusual, complex, elaborate, artificial, expensive, or futile (38,42). Thus, the distinction involves what is readily available or customary in medical practice, and the degree to which the treatment is accepted in the specialty (4,38,43).
Childress (12) believes that the more recent distinctions between ordinary and extraordinary direct attention toward customary medical practice, and away from underlying principles, such as patient autonomy, which are meant to assure the consideration of the patient's interests and preferences. The patient tends to disappear from view, in favor of the collective opinion of physicians, even though it is the patient's disease or problem that the physician treats with the technology in question. Such distinctions are also subject to interpretation. According to one study (44) conducted after the Natural Death Act was implemented in California, physicians in that state generally viewed respirators, dialysis, and resuscitators as artificial, but split evenly on intravenous feeding, while two-thirds viewed insulin, antibiotics, and chemotherapy as natural. In another survey (45) conducted by the National Hospice Organization, respondents identified oxygen therapy, blood transfusions, antibiotics, nasogastric tube feedings, intravenous lines, nasogastric suctioning, radiation therapy, chemotherapy, and surgery as both ordinary and extraordinary. The only treatment consistently identified to be extraordinary and curative was hyperalimentation.

Most recently, the terminology of whether a treatment is ordinary or extraordinary has changed to whether a treatment is a "benefit" or a "burden", or "proportionate" or "disproportionate". This change in terminology is generally considered favorable by ethicists, since it reflects an increased emphasis on the impact that the treatment has on the patient's total welfare, not just on its medical or physiologic effects (6,7,11,38). A treatment might be considered ordinary or extraordinary depending on the stage of the patient's illness in which it
is used (11,38). Kuhse (4) emphasizes that treatment is ordinary or extraordinary depending on the quality of life a patient will enjoy after treatment, which has nothing to do with the ordinariness or extraordinariness of the means of treatment. Lynn and Childress (42) state that the determination of whether a treatment is ordinary or extraordinary is not as important as the determination that this treatment is likely to provide the patient benefits which are sufficient to make it worthwhile to endure the burdens that accompany the treatment. Each option must be assessed, including nontreatment.

Benefits vs Burdens

All medical treatments, including artificial nutrition and hydration, provide both benefits and burdens (46). Some benefits of artificial feeding may be restoration of nutrition status or fluid balance, prolongation of life, increased ability to recover from the effects of other medical treatments, and possibilities for return to useful function (11,42). However, artificial feeding carries risks, such as infection and aspiration pneumonia.

The goal of providing artificial feeding must be determined: is it to prolong life, deliver kilocalories, or provide comfort (46)? Some health care providers believe that at the end of life, not eating is a natural way of letting go; since artificial feeding cannot reverse the underlying diseases, it will only prolong the dying process (46). When deciding the appropriateness of using any medical technology, including artificial feeding, one should consider whether the therapy is futile (3).
The crucial issue is whether the benefits of a treatment outweigh the burdens for a particular patient, from the patient's perspective (3,46). The medical team often tends to overestimate the benefits and underestimate the burdens of the treatments they use routinely, and overestimate the benefit of prolonging life, making an accurate diagnosis, or engaging in the treatment of disease (11). When the means of artificial feeding become invasive and painful, then the burden may become substantial. Also, any burdens that are related to the administration of artificial feeding, such as the repeated drawing of blood, or restraining the patient, must be considered (11). Brody and Noel (11) also mention the importance of assessing spiritual and emotional burdens, not just physical burdens. Repka (7) mentions some conditions in which nutritional support may impose disproportionate burden: in the presence of unbearable pain that cannot be relieved; when nutrition intervention itself causes unmanageable pain; when the disease causes physical limitation of initiating nutrition support; or when nutrition support exacerbates the disease. When artificial feeding becomes a disproportionate burden to the patient, the feeding may be terminated (9).

**Withholding vs Withdrawing Treatment**

Once having started a medical treatment, many health care providers find it very difficult to discontinue it. Withdrawing a treatment which has already been started seems to be a more serious action than withholding, or not starting a treatment, even when either choice is likely to end in death (34,42). However, for many ethicists, there is no moral distinction between withholding or withdrawing a life-sustaining medical treatment, including artificial
nutrition and hydration (2,6,12,34,42,47). This means that if a treatment is beneficial to a patient, it is justified; if and when a treatment ceases to be beneficial, it is no longer justified and should be discontinued (6). Whatever conditions warrant not starting a treatment initially should also justify stopping treatment later (34). Before any treatment is started or stopped, there must be an expectation of clear potential benefit that is not outweighed by the burden or cost to the patient (48).

Treatment withdrawal decisions, however, may be complicated by psychological factors. For patients and families, emotionally, it may be much harder to stop a treatment, especially if death is probable, than to start it (3,6,34). Sometimes, initiating a treatment creates expectations in the minds of caregivers, patients, and families that the treatment will be continued indefinitely or until the patient is cured (34,42).

By drawing a distinction between not starting and stopping treatment, poor decisions are possible. A treatment that may possibly save life or improve health is not started because the health care team is afraid of being locked into a treatment that cannot be terminated, even if it proves to be of little benefit and great burden to the patient (12,47). On the other hand, a treatment might be continued for longer than it is beneficial to the patient, even to the point where it is causing harm (47). The President's Commission (47) is clear that nothing in law makes stopping treatment a more serious legal issue than not starting it. In fact, the Commission believes that greater justification ought to be required to withhold than to withdraw treatment, since it is uncertain if a particular treatment will have positive effects before it has been tried. Annas (2) strongly suggests "trials" of
therapies, which can and should be discontinued when they cease to have any usefulness to the patient.

Killing vs Letting Die

According to Meilaender (49), the point of medical care is not just to ward off death, treat diseases, and keep the body alive when a patient can no longer function as a whole, integrated organism. Rather, medicine's purpose is not so much cure as care: restoring health when possible, and continuing care when that is not possible. A treatment is useless if it can do no more than prolong the course of a patient's dying, offering neither hope for cure or palliative care. A common view holds that physicians can allow patients to die by stopping or withholding life-sustaining treatment, but they are not permitted to kill patients (36).

The Quinlan decision (30) holds that the removal of the respirator from a permanently comatose patient is not the primary and significant cause of death. Rather, the death is to be seen as the result of pre-existing natural causes. Generally, the current view is that when a physician withdraws a respirator from a terminal patient, or from a patient existing without any prospect of recovering a meaningful life, this is a case of permitting death to occur, and of allowing natural causes to claim the patient's life (27). Connelly (28) emphasizes that removal of artificial feeding would also be a form of letting die or natural death, rather than actual killing. For example, when there is little hope of recovery, and a patient is unable to swallow because of advanced disease, if we do not intervene with artificial feeding, the cause of death is clearly the disease or condition and the overall
deterioration of body functions.

Winkler (27) offers one way of reasoning which avoids classifying withholding or withdrawing of life-sustaining treatments as homicide, which is related to the legal doctrine of "proximate" cause. In this interpretation, the existing pathology is seen as the proximate cause of death. In the case of artificial nutrition and hydration, if the treatment is discontinued, the patient's disease can be said to claim the patient's life through a fatal nutritional and hydrational deficit. The critically important point is that the artificial feeding cannot cure, improve, or ameliorate the patient's fundamental condition, which may be taken to cancel any duty to provide this treatment. Brock (36) offers the interpretation that if you kill someone, what you do is initiate a deadly causal process which leads to the person's death. However, if you allow someone to die, e.g., by withdrawing or withholding artificial feeding, you allow a deadly causal process which you did not initiate, the disease, to proceed to its result of a person's death. Meilaender (49) emphasizes that, while we are not always morally obligated to provide nutrition and hydration for a patient, we are obligated never to withdraw nourishment in order to aim at a patient's death. He adds that when we withdraw a treatment that is either useless or excessively burdensome, we do not aim at death, although we may foresee it, but rather we aim only at the kind of care which is now appropriate. McHugh (50) also refers to the matter of intent: if the withholding or withdrawing of nutrition is intended to cause or hasten death, the intention then is euthanasia, and the withholding or withdrawing is morally impermissible.

The President's Commission (47) addresses the issue of prolonging unbearable suffering in terminally ill patients
which only ends in death. They state that health care providers are authorized and obliged to use pain-relieving drugs and procedures with a patient's or surrogate's consent, even if an earlier death is likely to result. The Commission endorses allowing physicians and patients to select treatments known to risk death in order to relieve suffering as well as to pursue a return to health.

**Quality of Life**

A person's quality of life is difficult to determine; thus, ethicists disagree about the appropriateness of considering quality of life when making treatment decisions. What constitutes quality of life is highly individual, and the patient's values are paramount (5, 7, 51). Calman (51) defines quality of life from the patient's perspective. To this author, quality of life depends on present lifestyle, past experience, hopes for the future, and dreams and ambitions. It must include all areas of life and experience, and take into account the impact of illness and treatment. He believes that a good quality of life is present when the hopes of the individual are matched and fulfilled by experience, while a poor quality of life occurs when the hopes and expectations do not meet with the experience. Quality of life changes with time, and under normal circumstances, can vary considerably; a person's priorities and goals are modified by age and experience. One must try to help people reach the goals they have set for themselves and foster their personal growth. To Calman, a good quality of life is usually expressed in terms of satisfaction, contentment, happiness, fulfillment, and the ability to cope. Quality of life includes not only the impact of treatment and its side
effects, but recognizes the patient as an individual and as a whole person with body, mind, and spirit.

Holst (34) agrees that quality of life must encompass more than just biological existence, and must recognize that an individual derives essential meaning and personal fulfillment in life from a variety of sources. He states that allowing quality of life to be part of treatment decisions recognizes individual differences and supports the conviction that life itself is not an absolute good, but rather a relative good that enables a person to pursue other goods. Repka (7) states that for a few patients, quality of life translates into quantity of life. However, most terminally ill patients desire relief of pain, interaction with family and friends, and sometimes a desire to die at home. Calman (51) emphasizes that it is not possible to make value judgments about another's quality of life, since it is his own perception which matters. Some individuals are able to have a good quality of life even though they may appear to have major problems such as serious physical illness or poor social conditions.

Recommendations

Many physicians and ethicists (7,10,13,42,46,48,52,53) now agree that there is no absolute obligation to provide nutrition and hydration to all patients, and that it is ethical to withdraw or withhold artificial feeding from certain patients. Some conditions when artificial feeding may not be appropriate are: when a patient's condition is irreversible; when death is likely in the near future; if the illness is terminal; if the patient is in pain, severely debilitated, unresponsive, or severely demented; if the patient has poor quality of life; and if artificial
feeding is not in accord with the patient's interests or wishes.

Two authors mention general guidelines for ethical decisionmaking concerning nutritional support. Lynn (54) states that, first, when a patient cannot make her own choice, any medical intervention should be undertaken only when expected to improve the patient's well-being. This requires evaluating whether the conditions necessary to prolong life are too burdensome to the patient for the treatment to be worthwhile or beneficial. Second, balancing objectives and concerns of the treatment should respect the patient's autonomy by reflecting her individual preferences, including well-established patterns of behavior and value commitments. Third, any medical treatment, including artificial nutrition and hydration, may sometimes be contraindicated as being against the patient's best interests or personal preferences. A treatment is not justified if it does not offer a reasonable expectation of improving the patients' well-being and quality of life.

Meyers (43) outlines the physician's duties toward patients, relating them to deciding the appropriateness of treatment. The first duty is to provide competent medical care, including an appropriate treatment plan. Nontreatment must also be considered an option. The second duty is to consider the patient's wishes, regardless of whether they are consistent with medical indications. The third duty is to attempt to improve the patient's quality of life; this does not necessarily include prolonging the patient's life. The fourth duty is to consider the family's wishes, and attempt to understand and work within the social interaction of that family. The fifth duty is to consider what cost will be incurred in society,
including the psychological or emotional costs to the health care team. The sixth duty is to avoid litigation.

Belcher (55) emphasizes that, once death is clearly inevitable and imminent, the decision to withhold or withdraw artificial feeding is relatively easy. However, it can be difficult to decide when this point has been reached. He recommends a period of observation while using the treatment until the outcome becomes clear. Belcher believes that any benefit from the treatment is usually apparent within two weeks, and often much sooner. Similarly, Annas (2) and the Hastings Center (20) recommend time-limited trials of medical procedures for nutrition and hydration, as well as trials of forgoing such procedures, to determine the benefits and burdens of treatment.

Several authors provide recommendations for decisionmaking based on the condition of the patient. McHugh (50) provides the following guidelines to the Roman Catholic bishops of New York and New Jersey. In the unconscious, imminently dying patient, nutrition and hydration cannot reverse the dying process, and are now considered useless and burdensome. In the conscious, imminently dying patient, nutrition and hydration are useless, but may be provided if desired by the patient. In the conscious, irreversibly ill, not imminently dying patient, nutrition and hydration are not useless for sustaining life. They should be provided unless or until there is clear evidence of unreasonable burden for the patient. For the unconscious, nondying patient, feeding will sustain life, and its withdrawal brings about death by starvation and dehydration. Without any other indication of a definite burden for the patient, withdrawal of artificial nutrition and hydration in this case is not morally justifiable.
Callahan (56) describes the difficulties of making ethical decisions for elderly patients, emphasizing that the line must not be blurred between caring for the dying and hastening their dying for our benefit rather than theirs. Competent, alert elderly patients whose dying is being prolonged, perhaps painfully, by nutrition, would probably benefit from withholding or withdrawing the treatment. Elderly patients who are not dying, but are irreversibly comatose, also receive no benefit from artificial feeding, so the treatment could probably be stopped. However, if an elderly person is irreversibly demented, but not obviously in danger of imminent death or a totally vegetative state, Callahan sees no justification for withholding food and water. He states, however, that patients who constantly pull out feeding tubes should not be force fed. He emphasizes that age alone is never sufficient reason to terminate artificial feeding.

Koshuta et al (57) describe the philosophy of the Hospice of Washington (DC) on artificial nutrition and hydration. They have no policy which requires or bars this treatment, and develop a care plan for each individual patient. Generally, the likely benefits and burdens to the patient are assessed, and no obligation exists to continue artificial feeding if later assessment indicates that its withdrawal has become beneficial.

Two nutrition professional societies have published guidelines on providing artificial feeding. The American Dietetic Association (ADA) (58) stresses that, for a person in a persistent vegetative state (PVS), the rule should be followed of, "when in doubt, feed". Feeding should be started for a patient in a coma or an unconscious state as soon as he is medically stable, and should continue at least until a diagnosis of PVS is established, which is a
minimum of one month. Feeding should only be stopped after the patient is diagnosed as permanently unconscious, and the health care team has evidence of the patient's wish to stop nutrition and hydration. For terminally ill patients, the ADA (59) states that forgoing or discontinuing artificial nutrition support may be considered when some or all of the following conditions are present: death is imminent, within hours or a few days; artificial feeding will probably worsen the condition, symptoms, or pain; a competent patient has expressed an informed preference not to receive aggressive nutrition support that would be ineffective in improving his quality of life and/or which may be perceived by the patient as undignified, degrading, or physically or emotionally unacceptable; or if available and legally recognized written advance directives, such as the living will or durable power of attorney for medical care, may indicate the preference of an incompetent patient. The American Society for Parenteral and Enteral Nutrition (60) states that enteral nutrition should not be used whenever aggressive nutrition support is not desired by the patient or his legal guardian, and when such an action is in accordance with hospital policy and existing laws. Also, enteral nutrition may not be warranted in patients who are imminently dying, in an irreversible coma, or have an extremely poor prognosis with no hope for improvement.
REFERENCES


17. Ibid., 120-193.

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49. Meilaender G. The confused, the voiceless, the perverse: shall we give them food and drink? Iss Law Med. 1986;2:133-148.


KEY ISSUES DISCUSSED IN PART IV:

- The preferred way to feed a patient is orally. If this is not possible, enteral or parenteral means of feeding may be appropriate.

- Enteral feeding methods are used when the GI tract is functional. If the GI tract is not functional, parenteral nutrition, which inserts nutrients directly into the circulatory system, may be used.

- Both tube feeding methods involve complications, some of which may be serious.

- Tube fed patients may also experience psychosocial problems such as depression, poor body image, decreased sexual activity, grief, and distress from being unable to eat normally.

- Ethical analysis can provide a framework for making appropriate decisions about providing tube feeding for a seriously or terminally ill patient.

- The four ethical principles which must guide decisionmaking are: autonomy, nonmaleficence, beneficence, and justice.

- Many physicians and ethicists now agree that there is no absolute obligation to provide nutrition and hydration to all patients.
Dietary Intake of Older Adult Cancer Patients in Hospice

ABSTRACT

Daily food intake records were obtained for two days per week from 12 subjects (6 male, 6 female), with a mean age of 76 years (range 59 to 88) who were in hospice care at home. The number of records obtained from subjects ranged from 2 to 32, for a total of 134. All patients had advanced cancer; five patients died during the study, and one was nourished primarily with enteral formula through a gastrostomy tube.

The lowest and highest energy intakes for one day were 0 kcal (0% of the recommended intake [RI]) and 2809 kcal (122%). The mean daily energy intake for males ranged from 657 to 2142 kcal (28 to 93%), and for females, from 358 to 1852 kcal (18 to 97%). The lowest intake for one day for carbohydrate, protein, and fat were 0 g of each in one patient right before death. The highest intakes observed in the patients were 432 g (149% of the RI) of carbohydrate, 111 g (175% of the RDA) of protein, and 143 g (186% of the RI) of fat.

For all 12 subjects, zinc and pyridoxine were eaten in least amount, as compared to recommended levels, and vitamin C and thiamin were most plentiful in the diet. All six female subjects had mean daily intakes of less than 100% of the RDA for iron, zinc, vitamin D, and pyridoxine. Five of the six males had mean daily intakes of less than 100% of the RDA for zinc, vitamin A, and pyridoxine.
The five patients who died during the study had the lowest mean daily intakes of energy (358 to 1063 kcal), reported eating less food than before becoming ill, and had estimated body weight losses of 12 to 26%. The three patients who had the highest mean daily intakes of energy (1852 to 2124 kcal) exhibited the lowest amount of weight loss (3 to 7%), and reported eating the same amount of food as they had before becoming ill.

Food intake patterns for 4 of the 5 patients who died were examined. Three patients had steadily decreasing energy intakes during the last few weeks of life. The fourth patient exhibited his highest energy intake for one day on the day before his death.

The foods most commonly preferred by the subjects were: bread; milk; red meat, especially pork products; coffee; vegetables, especially potatoes; and sweets and desserts. Three patients ate varied diets, and five tended to eat the same foods or kinds of food most days.

This study represents an attempt to document what and how much food a small group of terminally ill cancer patients eat. In general, the patients ate whatever and as much as they wished, and tended to eat those foods which would not result in unpleasant symptoms. Also, several patients were able to survive for extended periods on very low intakes of food and fluids, with resulting low intakes of all nutrients.

INTRODUCTION

Cancer is a group of diseases characterized by the uncontrolled growth and spread of abnormal cells which can result in death. As of 1994, one of every five deaths in
the U.S. is from cancer (1). Approximately 75% of terminally ill patients are over the age of 55, and the most common cause of death in terminal patients is cancer (2).

Cancer is often associated with a host of clinical symptoms and conditions, such as nausea, vomiting, and weakness, which adversely affect food intake (3). Cancer treatment methods (4,5), use of medications to control symptoms (6), and psychologic and social factors (7-10) also affect food intake. The cancer patient is often malnourished, and malnutrition has been found to be associated with a poor prognosis (11,12). It would seem logical that nutrition intervention to improve nutrition status would improve prognosis also. However, the effectiveness of providing nutrition support to influence clinical outcome in cancer patients has not been established (13-16), and many authors believe that aggressive nutrition therapy does not significantly influence the outcome of patients with advanced cancer (17-21).

While many researchers have investigated the relationship between diet and the development of cancer, relatively few studies have examined the diets of patients who already have cancer (22-29). Even fewer studies document the dietary intakes of terminal cancer patients (30-32).

Walsh et al (30) assessed the voluntary dietary intake of 13 hospice inpatients for five consecutive days. Patients were 11 females and 2 males, age 56 to 83 years (median age 74) who had advanced cancer of different types. Weighed portions of food were served, and plate waste by weight was subtracted, to estimate individual intake. Corli et al (31) quantified the extent of nourishment and variations in food intake during the last weeks of life. Subjects were 75 patients, with a mean age of 67.6 years,
with advanced tumors requiring palliative treatment and receiving home care assistance. Patients completed daily records to describe their food intake of the previous 24 hours as "a lot", "normal", "little", "very little", or "nothing", and numerical scores were assigned for each level of food intake. Feuz and Papin (32) studied 116 elderly patients with terminal cancer, with an average age of 76 years, who were hospitalized until death. The purpose of this prospective, qualitative study was to determine whether certain modifications in therapeutic approaches would have a beneficial effect on nutrition behavior. The daily oral energy and nutrient intakes of patients were not measured.

Usually, the dietary intake of any patient, along with laboratory data, anthropometric measurements, and clinical evaluation, is used to assess his or her nutrition status. Subsequently, results of the nutrition assessment are used to make recommendations and plan interventions to improve the patient's nutrition status as necessary. However, for terminally ill patients, identifying malnutrition is prudent, but reversing malnutrition may not be possible or appropriate (33). The principal goals of palliative nutrition care, as contrasted to nutrition care to cure or treat an illness or condition, are to maximize the patient's nutrition benefit, pleasure, and comfort from food while minimizing discomfort from common symptoms (34).

Hospice patients are generally in their mid-to-upper 60's, and over 90% of them have cancer (35). In one study of hospice patients, more than 95% had died by 180 days from entering hospice care, and the average survival time was roughly two months (36). Several authors have observed that terminal patients can live comfortably for extended periods despite minimal, if any, intake of food and fluids.
In one reported case, an 83-year-old man with prostate cancer stopped eating and drinking two weeks before his death (38).

PURPOSE AND OBJECTIVES

Information about the dietary intake of terminal cancer patients is scarce, and the issue of the importance of maximizing food intake in cancer patients is controversial. Aggressive nutrition support especially in the terminal cancer patient may be inappropriate or harmful. The purpose of this study was to describe the dietary intake of older adult cancer patients in home hospice care. Specific objectives were: (1) to determine the intakes of energy and select nutrients; (2) to observe if dietary intake is related to survival; (3) to observe patterns in dietary intake as death approaches; and, (4) to identify foods commonly preferred by the patients.

SELECTION OF SUBJECTS AND METHODOLOGY

Subjects for this study were patients in a small, non-profit hospice in rural southwest Virginia. All subjects were age 59 years or older, had confirmed malignant disease, and were medically certified as having a life expectancy of six months or less. Subjects were also chosen who were not in denial about their terminal condition; were caring for themselves or receiving adequate daily care from family or other caregivers; had access to food; had the capability, or a caregiver with the capability, to understand and complete simple food intake
records; were not undergoing any curative procedure, such as chemotherapy or radiation therapy; and were not expected to die imminently. Suitable willing subjects were identified by the primary care hospice nurses and social workers.

The research was approved by the Institutional Review Board of Virginia Polytechnic Institute and State University for projects involving human subjects. At the first visit with the subject and/or caregiver, the purpose of the research was explained and informed consent forms were signed. Information was gathered on a Patient Data Sheet and included recent medical history, history of the cancer, medication use, food habits, and nutrition-related symptoms. A new Patient Data Sheet was completed monthly or as needed to document significant changes in the patient's food habits or health status. The patient and/or caregiver was given directions for completing the food intake records, and the directions were carefully explained. The recorder was asked to enter foods and beverages on the intake form right before serving, or right after eating, to maximize accuracy. It is reasonable to assume that this was done in most cases since almost all meals were eaten at home, and the recorder, especially if he or she was a caregiver, was very vigilant about the amount of food served and eaten. A diagram for estimating food and beverage portion sizes was also provided and explained. The person who agreed to complete the food intake records was given a supply of records, and was asked to complete two records per week, on a Friday and Saturday, or on a Sunday and Monday, and to mail them back to the researcher using the stamped, self-addressed envelopes provided. Three subjects who were unable to complete the forms were telephoned once or twice per week to gather the
necessary information. For these subjects, data collection was comparable to using the 24 hour recall method, since they reported the foods and beverages they had eaten and drunk previously, rather than as the items were served or eaten. Food records for one subject, MC, were completed twice, with a week between sets, for a total of four records. In addition, each person was telephoned approximately weekly to determine if any problems were encountered in completing the records, to answer any questions, and to be thanked for his or her help and cooperation in the study.

At all times, it was strongly emphasized that the purpose of the research was to document food intake in a descriptive manner. The patient and/or caregiver was reminded that there were no right or wrong foods, or amounts of food, which should be served or eaten. The food item and the amount, no matter how small, should be listed, and food habits should not be changed in any way.

Each patient or caregiver was asked to complete the food intake records for as long a period of time as possible. Thus, the number of records collected for each patient varied, depending upon how long they survived, and how long they wished or were able to complete the forms. A total of 134 daily records was obtained. All of the food items listed on the food intake records were manually coded and entered into the Nutritionist IV computer program (Version 3.0, 1993, N-Squared Computing, San Bruno, Ca.) for nutrient analysis.

The researcher felt that the food intake records obtained were accurate reflections of patient intakes. Initially, the primary care hospice nurses and the social workers mentioned the study to those patients and caregivers who they felt would be suitable subjects. Next,
the researcher met with those patients and caregivers who had expressed interest in participating, and carefully explained the tasks involved in being a participant. In some instances, the potential subject thought that the tasks were too burdensome, so he or she declined. In one case, the subject (AM) stopped participating after completing one set of records. Thus, it was felt that those who agreed to participate did so very willingly, were truly interested in the goals of the study, and made every attempt to be accurate. In addition, many of the subjects and family members who participated in this study were also participants in two other studies, which are reported elsewhere. The researcher felt that good rapport and ongoing communication were maintained with all participants.

For each subject, each daily food intake record was analyzed individually, and then an average for his or her entire set of records was obtained. The Nutritionist IV program provides both the amount of each nutrient and the percentage of the Recommended Dietary Allowance (RDA) which is met, based on gender and age of the subject. For those nutrients without an RDA (energy, fat, and carbohydrate), Nutritionist IV provides the percentage of the recommended intake (RI). Table 1 lists the reference values listed by the Food and Nutrition Board (41) for both the RDAs and the RIs, and used for nutrient analysis by Nutritionist IV.

The intakes of total energy, carbohydrate, protein, and fat were obtained. The intakes of eight specific nutrients were also examined: iron and zinc to represent meat intake; calcium and vitamin D to represent dairy intake; vitamins A and C to represent fruit and vegetable intake; and thiamin and pyridoxine to represent grain and legume intake. No complicated nutrient analysis was deemed
necessary since no attempt was made at nutrition assessment or intervention, or to improve nutrient status.

Appendices A through E contain the forms used in this study: Voluntary Informed Consent; Patient Data Sheet; Directions for Completing the Two-Day Food Intake Record; Diagram for Estimating Portion Sizes; and Food Intake Record for One Day.

RESULTS

Food intake records were obtained for 12 subjects (6 male, 6 female), age 59 to 88 years old (mean age 76), with different cancers (5 colon, 3 lung, 2 liver, 1 prostate, 1 mouth). The number of daily food records received for the subjects varied from 2 to 32, for a total of 134. For the two patients from whom only two records were received, one patient (AM) said she was too sick to complete the forms, and the other (PS) was discharged from hospice care. Several other potential subjects were contacted and agreed to participate, but almost immediately became too sick to complete the food intake records. In one case, the caregiver attempted to complete the forms, but found it too traumatic to participate. For eight patients, the primary caregiver was a family member; for one patient, a friend; and three patients cared for themselves.

Table 2 lists some characteristics of the 12 patients from whom food intake records were obtained and analyzed.
Intakes of Energy, Carbohydrate, Protein, and Fat

Table 3 lists the lowest, highest, and mean daily intakes for each patient of energy, carbohydrate, protein, and fat. The percentage of the RDA or RI based on sex and age (51+) are indicated in parentheses. All patients were nourished orally, except PS, who received almost all his nutrients from a formula through a gastrostomy tube (G-tube) which had been placed 18 months before his admission to hospice.

The lowest and highest energy intakes for one day observed in any of the subjects were 0 kcal (0% of RI) in female patient AR right before her death, and 2809 kcal (122%) in male patient GM. The lowest mean daily intake for a female patient of 358 kcal (18%) was observed in LA, for whom only four food intake records were obtained right before her death. The lowest mean daily intake for a male was 658 kcal (28%) in JJ. The highest mean daily intake for a male was 2142 kcal (93%) and for a female was 1852 kcal (97%). Because the number of food records obtained for the subjects varied greatly, a mean intake for all subjects is meaningless.

At least ten food intake records, representing at least five weeks of data collection, were obtained for six subjects. Of the six, the two subjects with colon cancer, GM and AR, and subject JJ with prostate cancer, had the lowest mean daily intakes of energy (59%, 19%, and 28% of the RI, respectively). Subjects HW and AJ with liver cancer showed mean daily energy intakes of 86% and 97%, respectively, and subject MD with lung cancer showed a mean daily intake of 93% of the RI.

Energy intake for one day varied widely in the six subjects for whom at least ten food intake records were
of the RI) for carbohydrate, 73 g (116% of the RDA) of protein, and 87 g (113% of the RI) of fat.

Of the six patients for whom at least ten food intake records were obtained, JJ and AR who died during the study had much lower intakes of carbohydrate, protein, and fat than the four subjects who survived, probably because these two patients also had lower mean daily intakes of energy.

Intakes of Select Nutrients

Tables 4 and 5 list the lowest, highest, and mean daily intakes of select vitamins and minerals for all 12 subjects. The percentage of the RDA based on sex and age (51+) for each nutrient are indicated in parentheses.

The lowest daily intakes of the eight vitamins and minerals listed were exhibited by female patient AR, who had virtually no intakes for any of the nutrients on three days. Three other patients, JJ, GM, and RM, had zero intakes for one day for at least one nutrient. The highest daily intakes were seen in different patients: for iron, 20.0 g (200% of the RDA) in patient AJ; for zinc, 23.7 g (147%) in PS, who received mostly enteral formula; for calcium, 2382 g (297%) in MD; for vitamin D, 11.49 mcg (226%) in GM; for vitamin A, 1903 RE (237%) in RM; for vitamin C, 867.7 g (1446%) in GM; for thiamin, 3.59 mg (359%) for AJ; and for pyridoxine, 2.91 mg (145%) in PS.

Of the five patients who died during the study, JJ and AR had mean daily intakes for all eight nutrients at levels below 50% of the RDA. Patients MC, RM, and LA had mean daily intakes at levels below the RDA for three, four, and seven of the eight nutrients, respectively. Patients JJ, AR, and LA also had the three lowest mean daily intakes of
energy of all the subjects.

There were four survivors among the group of six subjects for whom at least ten food intake records were obtained. These four patients, HW, GM, AJ, and MD, had mean daily intakes greater than 75% of the RDA for three, four, five, and six nutrients, respectively. For all four patients, mean daily intakes of zinc and vitamin A were below 75% of the RDA, and the mean daily intakes of vitamin C and thiamin were above 75% of the RDA. Three patients, HW, MD, and AJ, had mean daily intakes of iron which were greater than 100% of the RDA.

Of the eight nutrients examined for all 12 subjects, zinc and pyridoxine were eaten in the least amount. For both nutrients, only PS, who received mostly enteral formula, had a mean daily intake of greater than 100% of the RDA. The most plentiful nutrients were vitamin C and thiamin, which were present in amounts greater than 100% of the RDA for 8 and 7 of the 12 subjects, respectively. These higher intakes may have been a result of the subjects' preferences for orange juice and grapefruit, good sources of vitamin C, and for pork products, which are rich in thiamin. All six female subjects had mean daily intakes of less than 100% of the RDA for iron, zinc, vitamin D, and pyridoxine. When PS is not considered, the five remaining male subjects had mean daily intakes of less than 100% of the RDA for zinc, vitamin A, and pyridoxine.

**Dietary Intake and Survival**

Table 6 lists some information about patient survival, reported weight loss, and quality of intake during the study. Survival is calculated as the number of days the
patient lived from the date of admission to hospice until the date of death or the date of the last obtained food intake record. For all patients, the researcher asked about body weight before the illness and about weight at the time of entering the study. Usually, this information was estimated by the patient or caregiver, unless the patient had been weighed recently during a visit to the physician. A percentage of weight loss was calculated for each patient based on the estimates provided. Eight of the patients were estimated to have been of low to average weight before becoming ill, and the remaining 4 patients had been overweight. Based on the researcher's personal observations, JJ, PS, HW, and MD appeared very thin. JJ and PS had estimated losses of 24% and 20% of body weight, respectively. However, HW and MD reported losses of only 3% and 7% of body weight, respectively, and were believed to have been very thin men normally. AM, who reported losing 39% of her body weight, had been overweight initially, and did not appear emaciated. AJ, who reported a weight loss of 5%, had been overweight initially, and still appeared overweight.

At the first visit each patient and/or caregiver was asked whether food intake, in general, was more, less, or about the same since onset of the illness. Finally, information about the use of enteral formula is listed.

The five patients who died during the study had the lowest mean daily intakes for energy (358 to 1063 kcal), and all reported eating less food than before becoming ill. Patient AR used the formula Ensure occasionally, and LA regularly, as a supplement. However, during the last few days of her life, LA used Ensure as her only source of nutrition. All five reported an estimated body weight loss since becoming ill of 12 to 26%; a weight loss of 10% or
more is considered significant, and a sign of possible malnutrition (42). The five patients who died had survived from 74 to 124 days in home hospice care, which was considerably longer than the average survival time of two months reported in 1988 (36).

Of the seven patients who survived during the study, four reported eating less food than they had before becoming ill, and reported estimated losses of 17 to 39% of body weight. The remaining three patients (HW, AJ, and MD) who reported eating the same amount of food as they had before becoming ill showed the lowest weight losses of 3, 5, and 7%, respectively. These three patients also had the highest mean daily intake of energy (1852 to 2124 kcal).

Four of the 7 patients who lived used enteral formula, which was considered to be a food, not a supplement, in this study. Patient GM was not considered to be a user of formula since he used Ensure only once in nine weeks. HW used Ensure occasionally. PS received almost all of his nutrition from Osmolite HN through his G-tube. MD and WE used Ensure in amounts from 1 to 3 cups per day. For WE, who had mouth cancer with swallowing problems, Ensure was an important source of nutrition.

Overall, the survivors lived from over 25 to over 790 days in home hospice care.

Dietary Intake Before Death

The food intake patterns for four of the five patients who died during the study were examined to see if changes occurred as death approached. The pattern for patient RM was not examined since food records were received only until 16 days before her death. For patients LA and MC,
only four food intake records were obtained for each, and all were examined. For patients JJ and AR, only the last eight records for each were examined. In Figure 1, for each of the four patients, the energy intake for one day is plotted against the number of days before death this intake was recorded.

Patients MC, AR, and LA showed steadily decreasing energy intake during the last few weeks of life. Subject JJ also had a steadily decreasing food intake, then exhibited his highest energy intake for one day (1083 kcal) on the day before his death. The reason for this phenomenon is unknown, and his family could provide no explanation. In fact, the family reported that on the day of his death, JJ ate a small breakfast, a large lunch, and died about one hour later of apparent cardiac arrest. As mentioned previously, the daily energy intake for the patients varied considerably, even between consecutive days.

JJ ate regular foods right up until the time of death. MC ate regular foods until two days before death, when she began taking only water. AR ate regular food, stopped eating five days before she died, then took only water. LA stopped eating food three days before death, and drank water and Ensure the last few days.

Food Preferences

The food intake records for the eight patients for whom at least six records were obtained were examined to identify foods that were commonly eaten. A food was considered to be eaten on a day, without regard to the amount or number of times eaten. The majority of patients
tended to eat the same foods or kinds of foods every day. Also, except for drinking Ensure, all eight patients were eating traditional American or Southern foods. Figure 2 lists the foods each patient recorded at least once on at least 50% of his or her records. Figure 3 lists the protein sources they favored.

The types of foods which were preferred by at least four of the eight patients were: bread, milk, red meat, coffee, vegetables, and sweets and desserts. For all patients, the types of bread most commonly eaten were white bread, biscuits, and cornbread. Common milk products used were whole, reduced fat, and buttermilk. Beef was rarely eaten, and the red meats preferred were pork products, such as ham, bacon, and sausage. Five of the 8 patients drank at least one cup of coffee per day. Potato was the most commonly eaten vegetable, and other favorites were sweet potatoes and corn. Sweets and desserts were commonly eaten, including cake, pie, cookies, ice cream, and pudding. Patients preferred cola type soda and orange juice. Commonly eaten fruits were banana, applesauce, and grapefruit. The favored cereals were oatmeal and cold breakfast cereals.

Three patients, AJ, GM, and RM, ate varied diets. Patients HW, JJ, MD, AR, and WE tended to eat the same foods most days. WE, who had mouth cancer with swallowing problems, depended on Ensure and certain other foods which he knew from experience would not cause choking. HW worked and cared for himself, and ate mostly prepared foods to save time and effort. Breakfast and lunch always consisted of the same foods, and were eaten or prepared in a restaurant. Dinner almost always consisted of a frozen dinner with an additional canned vegetable. The most commonly eaten protein sources were chicken, eggs, ham, and
sausage. Patients JJ and HW consumed no dairy products or coffee, and MD ate no fruit. Yet, HW drank Ensure occasionally, and MD drank it regularly, so that the formula served as a source of vitamins and minerals on their somewhat restricted diets.

**DISCUSSION**

**Intakes of Energy, Carbohydrate, Protein, and Fat**

In this study, the mean daily intakes of energy for the 12 subjects ranged from 358 to 2142 kcal. Two of the 12 patients had mean daily energy intakes of 93 and 97% of the RI. These results are similar to those of Theologides et al (23) who studied 39 patients with various cancers who were not undergoing treatment. Eighteen patients, who exhibited a loss of greater than 10% of their usual body weight prior to their study, showed mean daily intakes of 301 to 2241 kcal. Four of 21 patients who had not exhibited weight loss before the study had mean daily intakes ranging from 453 to 1351 kcal. The remaining patients had energy intakes which were comparable to healthy controls, and which met or exceeded recommended levels. Walsh et al (30) studied the voluntary diet of 13 hospice inpatients for five consecutive days, and found that the mean energy intakes ranged from 224 to 2137 kcal per day. These results are very similar to those of this study, probably since both subject populations were hospice patients.

Bass and Cox (29) used three day food intake records with 62 patients with various cancers who were at an early stage of treatment. They determined that females and males
had mean daily intakes of energy of 1480 and 1686 kcal, respectively, which were below 100% of recommended levels. Costa et al (24) used 24 hour recalls with 199 patients with various cancers, most of whom were undergoing chemotherapy. Results showed that male and female patients consumed a mean of 1894 and 1556 kcal, respectively, for that day.

With regard to energy intake, results of this study are comparable to those of Theologides et al (23) probably because in both studies, food intake data were collected over a period of time, and patients were not undergoing treatment. The mean energy intakes observed in this study were much lower than those observed by Costa et al (24) and Bass and Cox (29). In these latter two studies, three day records or 24 hour recalls were used, and patients were probably at earlier stages of disease, since they were undergoing treatment.

In this study, the ranges of the mean daily intakes for carbohydrate, protein, and fat for all 12 subjects were 51 to 274 g, 12 to 73 g, and 11 to 87 g, respectively.

Walsh et al (30) found that daily intakes of carbohydrate, protein, and fat ranged from 21 to 194 g, 11 to 86 g and 9 to 93 g, respectively. These results are somewhat lower than the ranges found in this study, and might be attributed to the fact that the subjects in the study by Walsh et al (30) were inpatients, while the subjects in this study were eating at home. Bass and Cox (29) found that female and male patients had mean daily intakes of protein of 59 and 66 g, respectively, which fall within the ranges observed in this study.
Intakes of Select Nutrients

For this study, intakes of only eight vitamins and minerals were examined, since it was believed that in-depth nutrient analysis was probably of little significance. No attempts were made to modify the diets of the subjects to increase nutrient intake. Also, the effects of a deficiency of any nutrient are probably unknown, since terminal patients, like those in this study, are in an advanced state of disease and consume multiple medications. Analysis was done to determine intakes of iron and zinc to represent meat in the diet, calcium and vitamin D to represent dairy products, vitamins A and C to represent fruit and vegetables, and thiamin and pyridoxine to represent grains and legumes.

If subject PS on enteral formula is not considered, the five remaining male subjects had mean daily intakes of less than 100% of the RDA for vitamin A, zinc, and pyridoxine. The six female subjects had mean daily intakes of less than 100% of the RDA for iron, vitamin D, zinc, and pyridoxine. Eight and 7 of the 12 subjects had mean daily intakes of greater than 100% for vitamin C and thiamin, respectively.

Limiting discussion to the eight select nutrients, similar results are found in the literature. Costa et al (24) found that intakes of iron, zinc, vitamin D, and pyridoxine were significantly decreased in cancer patients than in controls. Bass and Cox (29) found that female cancer patients had significantly lower intakes of vitamin A, thiamin, and zinc, and significantly higher mean intakes of vitamin C and pyridoxine, than the general population. Mean intakes of male cancer patients were significantly lower for vitamin A, pyridoxine, calcium, and zinc, and
higher for vitamin C. Walsh et al (30) found that hospice patients had lower intakes of iron, and higher intakes of calcium, compared to recommended amounts.

Because of limited food intake in hospice patients, it is quite possible that they are deficient in some vitamins and minerals. Without biochemical analyses, it would be almost impossible to know if a deficiency state for a specific nutrient were present in any of the patients. Also, attributing the presence of a symptom, such as loss of taste or skin breakdown, to a vitamin or mineral deficiency is questionable in such patients. Yet, the possibility of one or more deficiencies must be acknowledged and considered when formulating a nutrition care plan for the terminal patient. The longer a patient survives with minimal food and fluid intake, the more likely the development of deficiency symptoms. Thus, when a patient is observed to survive for an extended period, perhaps more care must be taken to assure maximal food and nutrient intake. At the least, perhaps such patients should be encouraged to use nutrient dense enteral formulae or some other type of vitamin and mineral supplement.

Dietary Intake and Survival

To date, it is unclear whether the weight loss seen in cancer patients is due primarily to reduced food intake, increased energy expenditure, or a combination of both (43,44). Studies have provided conflicting evidence with some showing increased energy expenditure, and others showing energy expenditure to be normal (45). Even a mild increase in metabolic rate must be met by an equivalent increase in energy intake or persistent weight loss will
ensue (46). However, it has been found that in cancer patients, food intake fails to adjust to changes in the metabolic rate (46), and studies of the impact of weight loss on survival provide conflicting results.

Costa et al (24) found that, in general, although cancer patients ate less than controls, patients who lost weight did not eat less than patients who maintained weight. Also, in lung cancer patients, reduced food intake could not account for an observed reduction in weight from an average of 112% to 96% of ideal weight. They concluded that weight loss in cancer patients might not be due in all cases to inadequate food intake. Dewys et al (12) found that, for patients with most common solid tumors, a decrease in survival rate of from 30 to 50% was associated with even moderate degrees of weight loss of less than 5% of body weight.

Results in this study were less conflicting. In the five patients who died, body weight loss ranged from 12 to 26%, and all reported eating less food than before becoming ill. Of the seven patients who survived, the three who had the highest mean daily intake of energy also exhibited the lowest body weight loss. The patient who survived the longest was AJ, whose mean daily intake of energy met 97% of the RDA and who has spent 790+ days in hospice.

Attempts to relate weight loss to survival must be made with caution. To date, it is not known whether malnutrition causes shortened survival or is secondary to other processes which shorten survival (31). The question yet to be resolved is whether low food intake leads to death, or if approaching death leads to decreased food intake. This question is especially difficult to answer in older adult terminal patients, since many old and sick persons generally have small appetites and low activity
levels; symptoms which can decrease food intake may be present; and medications which can decrease appetite may be used. Also, patients enter hospice care at different levels of illness and debilitation. Some physicians recommend patients to hospice as soon as the terminal diagnosis is made. Such patients are often still active and feeling relatively well. In other cases, physicians do not send the patient to hospice until death is imminent, so the patient may survive a much shorter period of time.

Persons who work with the terminally ill have observed that these patients can survive for extended periods on very little food (37-39). This observation was seen in this study. Three patients, JJ, AR, and GM participated in this study for 44, 58, and 58 days, respectively. Food intake records for JJ and AR were obtained until several days before death, and GM was still alive at the conclusion of the study. The mean daily intake of energy for these three subjects over a time period of almost two months were 657 kcal (28% of the RI) for JJ, 365 kcal (15%) for AR, and 1366 kcal (59%) for GM. Patient PS, who had received his G-tube 18 months before admission to hospice, and who had spent an additional 324 days in hospice at the time of the study, had survived for more than two years on approximately 1400 kcal per day. These four patients were neither physically active, nor bedfast, and exhibited estimated losses of body weight between 17 and 24%. All were very thin at the time of the study.

Dietary Intake Before Death

In this study, there were four patients, JJ, AR, LA, and MC, for whom food intake records were obtained to
within six days before death. Three of the 4 patients exhibited an overall steady decrease in food intake during the last three weeks of life. LA and MC stopped taking food two to three days before death, and AR took only sips of water for the last four days. JJ ate solid food until an hour before he died.

Results in the present study agree with those of Corli et al (31), who found that patients with advanced tumors in palliative treatment and receiving home care assistance exhibited a steadily decreasing food intake during the last four weeks of life. Peuz and Rapin (32) observed that 107 of 116 (92%) of elderly terminal cancer patients who were hospitalized had meals until the day they died. The nine remaining subjects stopped eating an average of 3.5 days before they died.

**Food Preferences**

In this study, the food intake records of eight patients were examined to determine what foods were preferred. At least 4 of 8 patients preferred the following foods: bread, milk, coffee, vegetables, sweets and desserts, and red meat, consisting mainly of pork products. The patients' preferred protein sources were ham, sausage, chicken, eggs, and cheese. Several consumed soda and orange juice as beverages, and the favorite vegetable was potatoes.

Dewys and Walters (47) found that many cancer patients preferred highly sweet foods, and reported an aversion for meats, especially red meats. Ten of the 50 patients reported a bitter taste for coffee and chocolate. Gormican (48,49) surveyed cancer care institutions, and found that
adult cancer patients most frequently preferred juices, soda, dairy products, eggs, and mashed potatoes. The patients also exhibited strong aversions for red meats, poultry, and fish. Vickers et al (50) found that 111 cancer patients rated the following foods as least pleasant: red meats, other meats, fish, poultry, cereal products, sweet foods, and salty foods. Also, 42% of the patients reported a taste change for coffee.

Dixon et al (51) surveyed 35 nurses with hospice programs and public health departments, who reported their observation that many deteriorating hospice patients prefer foods typically consumed at breakfast. Also, many reject meat, coffee, rich foods, and sweets.

Comparing the results of the above studies to each other and to this study reveals contradictions in food preferences. Generally, it appears that patients in this study preferred red meats and coffee which are usually avoided. It is possible that the high intake of pork products in this population represents a general preference for Southern foods. The preferences reported by Cormican were most similar to those reported by subjects in this study.

CONCLUSIONS AND IMPLICATIONS

The dietary intake of terminal patients, including those with cancer, is a poorly researched area. Yet, food intake and nutrition can be an important part of life for such patients, even if prognosis or survival is not improved. For family members, feeding the patient is associated with expressions of care, love, and nurturing (51). For the patient, familiar foods can be a source of
comfort, continuity, and stability, and provide a focal point for patient-family interaction (52). For patients who want to eat and who can be helped to eat better, the importance of improving appetite and enabling them to eat as normally as possible cannot be overestimated (53).

Holden (54) interviewed 14 hospice patients and their caregivers, and found that a patient's loss of appetite was a source of anxiety and conflict within the family. The amount of food and fluid a patient took in was used to assess his or her overall condition. Caregivers frequently reported anorexia to be of greater concern than other problems associated with caring for the patient. Patients believe nutrition to be an important aspect of their care. Feuz and Rapin (32) mention a study (55) of 30 patients and 30 physicians and nurses at a geriatric ward in Geneva, Switzerland. The survey showed that only 10% of the doctors and nurses considered nutrition to be part of the patient's treatment; 30% considered nutrition to be related only to the patient's comfort and quality of life; and the remaining 60% did not consider that nutrition played any role in patient care. Conversely, 80% of patients considered nutrition to be an integral part of their treatment; they believed appropriate nutrition could enhance not only their comfort and quality of life, but also their survival. This Swiss study appears to reflect both the patients' concern, and lack of concern on the part of health care professionals and researchers, about the importance of food intake and nutrition for elderly, terminal patients.

Finding ways to improve nutrition for terminal patients and maximizing their pleasure and comfort from eating is also important since these patients can live for a very long time. In this study, AJ, PS, and WE had
already survived more than 790, 324, and 217 days, respectively, in hospice care, even though upon admission, each was given a prognosis of six months or less. Suggestions to improve oral intake for terminal patients include: providing food that is well-liked (56); offering several small meals per day instead of three large ones (57); and using medications to improve appetite and mood (53).

Aggressive nutrition therapy, including artificial methods of feeding and hydration, may not be warranted for terminal patients, depending upon the length of time they are likely to survive, and if it will improve the patient's life and not merely prolong death (21). Rather, nutrition for the terminal patient should maximize the patient's pleasure, comfort, and benefit from food, while minimizing discomfort from eating (58). Long-standing dietary restrictions based on rationales for preventing and treating chronic disease should not be imposed, except when physical discomfort results (21,34,59,60). Many of the patients in this study were instructed to "eat whatever you want, and as much as you can", which seems to be practical and helpful advice. Sometimes, patients may force themselves to eat to please family members, and may feel bloated or nauseated as a result (57). Holden (54) found that hospice patients wished family members to be less assertive in feeding activities, and should simply let them choose what and how much they wanted to eat. The patients in the present study were urged by caregivers to eat as much as possible, and every effort was made to serve foods which would please the patients. Those patients who cared for themselves knew from experience which foods could be tolerated, and would not result in troublesome symptoms.
Many health care professionals who work with terminally ill and hospice patients believe that it is normal for such patients to lose their appetites in the dying process (57,61). This belief was illustrated in this study by both the patients who lived for several months on very little food, and by those patients whose intake gradually declined in the last few weeks before death.

Because of the scarcity of information available about the food and nutrition needs of terminally ill cancer patients, this study presents an attempt to document what and how much these patients eat, how much or little food such patients appear to require, and how much or little food such patients can be expected to eat. Comparison of the subjects to control subjects would not appear to be necessary in such a study, since terminal patients are not only dissimilar to each other, but also have very different nutrition wants and needs from normal, well individuals. All of the subjects were seriously ill, and most were substantially older than the oldest category mentioned in the RDAs (51+). However, using the RDAs as reference points appeared to be the best method to compare the dietary intakes of the patients to each other, and to give at least some indication of the differences from intakes in well individuals.

Much more research is needed on the food and nutrition needs of seriously and terminally ill older adults. The results seen in this study may apply only to hospice patients at home. Other studies are needed with palliative care patients, not only in home hospice care, but also in hospital palliative care units, in home health care agencies, and in nursing homes.
REFERENCES


Table 1: Reference values used in the Nutritionist IV program for nutrient analysis: Recommended Dietary Allowances (41) and recommended intakes (41) by sex and age.

<table>
<thead>
<tr>
<th>NUTRIENT</th>
<th>MALE, 51+</th>
<th>FEMALE, 51+</th>
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</thead>
<tbody>
<tr>
<td>Energy, kcal*</td>
<td>2300</td>
<td>1900</td>
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<tr>
<td>Carbohydrate, g* (50% of energy requirement)</td>
<td>288</td>
<td>238</td>
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<tr>
<td>Protein, g</td>
<td>63</td>
<td>50</td>
</tr>
<tr>
<td>Fat, g* (30% of energy intake)</td>
<td>76.7</td>
<td>63.3</td>
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<tr>
<td>Iron, mg</td>
<td>10</td>
<td>10</td>
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<tr>
<td>Zinc, mg</td>
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<td>12</td>
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<tr>
<td>Calcium, mg</td>
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<td>800</td>
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<tr>
<td>Vitamin D, mcg</td>
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<td>5</td>
</tr>
<tr>
<td>Vitamin A, RE</td>
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<td>800</td>
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<tr>
<td>Vitamin C, mg</td>
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<td>60</td>
</tr>
<tr>
<td>Thiamin, mg</td>
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<td>1.0</td>
</tr>
<tr>
<td>Pyridoxine, mg</td>
<td>2.0</td>
<td>1.6</td>
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</table>

* Recommended intakes; all other values listed are RDAs
Table 2. Patient characteristics (n=12)

<table>
<thead>
<tr>
<th>PATIENT</th>
<th>SEX / AGE (YEARS)</th>
<th>CANCER SITE</th>
<th>NO. RECORDS COMPLETED</th>
<th>CAREGIVER (F,S,O) ***</th>
</tr>
</thead>
<tbody>
<tr>
<td>JJ*</td>
<td>M / 83</td>
<td>prostate</td>
<td>14</td>
<td>F</td>
</tr>
<tr>
<td>LA*</td>
<td>F / 76</td>
<td>colon</td>
<td>4</td>
<td>F</td>
</tr>
<tr>
<td>MC*</td>
<td>F / 87</td>
<td>colon</td>
<td>4</td>
<td>F</td>
</tr>
<tr>
<td>AM</td>
<td>F / 67</td>
<td>colon**</td>
<td>2</td>
<td>F</td>
</tr>
<tr>
<td>PS</td>
<td>M / 74</td>
<td>lung</td>
<td>2</td>
<td>F</td>
</tr>
<tr>
<td>GM</td>
<td>M / 77</td>
<td>colon**</td>
<td>18</td>
<td>F</td>
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<td>HW</td>
<td>M / 77</td>
<td>liver</td>
<td>18</td>
<td>S</td>
</tr>
<tr>
<td>MD</td>
<td>M / 66</td>
<td>lung**</td>
<td>10</td>
<td>S</td>
</tr>
<tr>
<td>AJ</td>
<td>F / 82</td>
<td>liver</td>
<td>32</td>
<td>O</td>
</tr>
<tr>
<td>AR*</td>
<td>F / 88</td>
<td>colon**</td>
<td>18</td>
<td>F</td>
</tr>
<tr>
<td>RM*</td>
<td>F / 78</td>
<td>lung</td>
<td>6</td>
<td>F</td>
</tr>
<tr>
<td>WE</td>
<td>M / 59</td>
<td>mouth</td>
<td>6</td>
<td>S</td>
</tr>
</tbody>
</table>

* died during study  
** with metastasis  
*** F = family member, S = self, O = friend
Table 3. Individual intakes of energy, carbohydrate, protein, and fat: lowest, highest, and mean values, with percentage of RDA or recommended intake for age and sex.

<table>
<thead>
<tr>
<th>PATIENT</th>
<th>KCAL</th>
<th>CHO (g)</th>
<th>PROTEIN (g)</th>
<th>FAT (g)</th>
</tr>
</thead>
<tbody>
<tr>
<td>JJ</td>
<td>389 (16)</td>
<td>32 (11)</td>
<td>3 (5)</td>
<td>7 (9)</td>
</tr>
<tr>
<td></td>
<td>1083 (47)</td>
<td>171 (59)</td>
<td>33 (52)</td>
<td>38 (49)</td>
</tr>
<tr>
<td></td>
<td>657 (28)</td>
<td>106 (36)</td>
<td>17 (26)</td>
<td>19 (25)</td>
</tr>
<tr>
<td>LA</td>
<td>219 (11)</td>
<td>30 (12)</td>
<td>8 (15)</td>
<td>8 (12)</td>
</tr>
<tr>
<td></td>
<td>604 (31)</td>
<td>97 (40)</td>
<td>21 (41)</td>
<td>17 (26)</td>
</tr>
<tr>
<td></td>
<td>358 (18)</td>
<td>55 (22)</td>
<td>12 (24)</td>
<td>11 (17)</td>
</tr>
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Note: values listed include use of enteral formulae but not of any other supplements
Table 4. Individual intakes of iron, zinc, calcium, and vitamin D: lowest, highest, and mean values, with percentage of RDA for age and sex.

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<th>CALC (mg)</th>
<th>VIT D (mcg)</th>
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Note: values listed include use of enteral formulae but not of any other supplements.
Table 5. Individual intakes of vitamin A, vitamin C, thiamin, and pyridoxine: lowest, highest, and mean values, with percentage of RDA for age and sex.

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<th>PYRIDOXINE (mg)</th>
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Note: values listed include use of enteral formulae but not of any other supplements
**Table 6.** Length of survival, estimated percentage of weight loss, and quality of intake for patients (n=12)

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<th>% WEIGHT LOSS</th>
<th>DESCRIPTION OF INTAKE</th>
<th>FORMULA (cups/day)</th>
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<tr>
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<td>(G-tube)</td>
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<td>17</td>
<td>less</td>
<td>no</td>
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* died during study
+ alive at conclusion of study
FIGURE 1. Daily energy intake during the last weeks of life for four patients.
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**FIGURE 2.** Foods listed on at least 50% of food intake records for each of eight patients.
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<th>HW</th>
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**FIGURE 3.** Common dietary sources of protein for eight patients
Tube Feeding: What Do Hospice Patients and Their Families Want?

ABSTRACT

Fourteen hospice patients and 18 family members of hospice patients were interviewed about their perceptions, knowledge, attitudes, and wishes concerning the use of artificial nutrition and hydration for seriously and terminally ill patients. Patient subjects were 7 males and 7 females with a mean age of 73.3 years (range 59 to 83) who had different types of cancer and had a life expectancy of six months or less. Family member subjects, including one friend, were 6 males and 12 females with a mean age of 58.0 years (range 22 to 79), who were primary caregivers for, or spent a good deal of time with hospice patients. Patients and family members were not matched; only six patients were interviewed with whom at least one family member was also interviewed.

A structured interview of 22 questions was administered to all subjects, and the term "tube feeding" was used to refer to all types of parenteral and enteral feeding methods except normal oral intake. During and at the end of the interview, subjects were encouraged to provide their opinions and comments about the subject of tube feeding for seriously or terminally ill patients.

Responses to the questions indicated that in general, patients were less opposed to the use of aggressive means of nutrition support than were family members. Three of
the 14 patients, and only one family member indicated that they would want tube feeding if they became unable to eat and drink by themselves. Eight patients and 14 family members thought that in some circumstances, tube feeding could be withdrawn from a patient who was already being tube fed. Three patients and none of the family members thought that persons must always be given tube feeding if unable to eat and drink by themselves.

Both patients and family members most often mentioned circumstances related to patient autonomy and prognosis as reasons why it would be permissible to withhold tube feeding from a patient.

This study represents a modest attempt with a small number of subjects to determine the opinions of hospice patients and their families about the use of tube feeding. Results seemed to indicate that discussion was not taking place among hospice patients, their family members, and their health care providers about the possible use of nutrition support for the patient. Also, since three of 14 patients indicated that they had decided to accept tube feeding for themselves, these patients may not be familiar with or accepting of the concept of palliative care as opposed to aggressive treatment. The opinions and wishes of terminal patients and their families must be considered by health professionals who make decisions or recommendations about the use of aggressive nutrition support for such patients.
INTRODUCTION

Modern medical technology, such as artificial feeding, mechanical ventilation, and kidney dialysis, can totally support patients and prolong life indefinitely (1-4). Even if such technology is ultimately unable to conquer death, it can determine the conditions and time of its occurrence (4).

Artificial means of nutrition and hydration may be indicated for a short time, e.g., following surgery when a patient is temporarily unable to eat (5). Long-term artificial feeding may be indicated for conditions such as strokes, premature birth, severe neuromuscular diseases, or anorexia associated with cancer or its treatment (5). However, many health care providers who work with hospice and palliative care patients do not believe that artificial nutrition and hydration should be routinely used for such patients. Also, the assumption that nutrition support will benefit terminal patients has not been clearly established (6,7).

Several authors (6,8-12) believe that the dying patient loses interest in food, and finally is unable to naturally ingest food and water. This is an adaptive process that allows the patient to die with less suffering, and aggressive nutrition support may result in more harm than good. As the patient spontaneously decreases food intake, nausea, vomiting, and abdominal pain decrease, especially where there is a bowel obstruction, liver disease, or malignant ascites (11). Also, after the decision is made not to use artificial feeding, many patients experience a sense of relief and a renewed sense of control when they do not have to force themselves to eat under threat of tube feeding (11).
As death approaches, patients gradually lose their desire to drink (13). Dehydration in terminally ill patients results from inadequate fluid intake; gastrointestinal and renal fluid loss; normal fluid loss from the skin and lungs; and from failure to replace these losses (14,15). In current practice, physicians often provide intravenous (IV) infusions to dying patients in the belief that dehydration and electrolyte imbalance are painful and stressful conditions (12,14,16). A dying patient on an acute medical-surgical unit who stops eating and drinking may automatically have an IV inserted without consideration of its potential benefits or detrimental effects (17,18). Also, in the home setting, families may request hospital admission for a patient who stops eating and drinking, with the belief that IV fluids may postpone death (17). However, there is no evidence to support the conclusion that providing fluids prolongs life (19). It is senseless to continue fluids after a decision has been made to discontinue food (11).

Research regarding the attitudes of patients, physicians, and nurses to artificially prolonging life, euthanasia, and withholding or withdrawing life support has been limited. Even fewer studies directly address the use of artificial nutrition and hydration, especially for terminally ill patients.

In this paper, the term "tube feeding" is used to include all enteral and parenteral means of providing food or fluids when normal oral intake is not possible.

The overwhelming majority of articles which specifically address tube feeding involve surveys or questionnaires of doctors and nurses who work in hospitals, hospice, or nursing homes. Generally, one or more hypothetical vignettes are presented, and the subjects are
asked for treatment decisions, opinions, and comments (18,20-25). In other studies, the health care professional is asked about his or her perceptions of tube feeding (6,26). Other research examines several life sustaining technologies, and tube feeding is one of the methods addressed (27-29). One study was found which determined the attitudes and opinions of dietitians about feeding the terminally ill (30), and in two studies, older adults were asked about decisionmaking regarding tube feeding (31,32). A literature search revealed no studies in which terminally ill patients and their family members were asked their attitudes, opinions, and desires about tube feeding. This population faces decisions about tube feeding when oral intake is no longer possible, and for them, serious illness and the possibility of imminent death are not hypothetical situations. For this reason, this study was undertaken to determine the perceptions, knowledge, attitudes, and wishes of hospice patients and their family members.

PURPOSE AND OBJECTIVES

The purpose of this study was to determine the perceptions, knowledge, attitudes, and wishes of patients in home hospice care and their caregivers, family members, and friends about tube feeding for seriously and terminally ill patients. Since these persons are facing the issue of deciding about the use of tube feeding for themselves or a relative in the near future, their opinions will be valuable and important to health care providers who work with the terminally ill.
SELECTION OF SUBJECTS AND METHODOLOGY

Subjects for this study were patients in two small, non-profit hospices in southwest Virginia, and their caregivers, family members, and a friend who lived with a patient. All patient subjects were age 59 years or older, had confirmed malignant disease, and were medically certified as having a life expectancy of six months or less. Patient subjects were chosen who were not in denial about their terminal condition; were caring for themselves or receiving adequate daily care from family or other caregivers; who were not expected to die imminently; and who were capable of, and willing to answer a series of questions for the researcher. Family member subjects (this term includes the one friend who was interviewed) were chosen who were caregivers for, or spent a good deal of time with a hospice patient; were not in denial about the terminal nature of the patient's condition; and were capable of and willing to be interviewed. Suitable potential subjects were identified by the primary care hospice nurses.

Patients and family members were not matched. In some cases, patients were too sick to be interviewed; for some patients, more than one family member was interviewed; and for other patients, no family member was available. A total of 14 patients and 18 family members were interviewed. For six patients, one or more family members were also interviewed.

The research was approved by the Institutional Review Board of Virginia Polytechnic Institute and State University for projects involving human subjects. At the visit to the patient's home, the purpose of the research was explained to the subject(s) and the informed consent
form was signed. Some background information was gathered about the patient, including gender, age, level of education, diagnosis, date of admission to hospice, and history of the illness. Family members were asked their relationship to the patient. All subjects were interviewed in person, except for two family members who were interviewed by telephone.

The researcher administered a structured interview of 22 questions to all subjects. It was explained that the questions referred only to the use of artificial feeding and receiving fluids using a medical procedure, and not to eating and drinking normally by mouth. Also, for simplicity, the questions referred to "tube feeding", meaning any artificial methods, including intravenous (IV). Subjects were encouraged to ask questions for clarification and make any comments they wished as the interview progressed. At the end of the interview, subjects were asked if they wished to make any additional comments or statements about the subject of tube feeding.

It was found that some introductory conversation about the patient and/or the person being interviewed, the issue of tube feeding, and the research project was helpful before launching into the questions, which could trigger an emotional response in some people. It was mentioned that the issue which would be discussed had appeared in the news media, in connection with cases such as those of Karen Anne Quinlan (33) and Nancy Cruzan (34). No other background information about the issue of tube feeding was discussed, other than the fact that using such procedures is controversial for some patients who are seriously or terminally ill. Subjects were also told that to the researcher's knowledge, hospice patients and their family
members had never been asked their thoughts and opinions about the issue of tube feeding.

The researcher attempted to be sensitive at all times to the concerns and opinions expressed. All subjects were willing to answer the questions. Most had additional comments, and some had stories to share about other family members who had received some form of tube feeding during the dying process.

Several of the 22 questions were adapted from three other surveys (32,35,36). Fifteen of the questions required a response of "yes", "no", or "I don't know". The answers to five of the remaining questions were dependent upon previous responses, and not all of these five questions were answered by all respondents. A total of five questions required answers which could include several opinions or answers. For these questions, no choices were provided by the interviewer, and all responses were given spontaneously by subjects. The questionnaire itself listed several possible choices for these questions to minimize writing for the interviewer.

Nineteen of the 22 questions were the same for both patient and family member subjects. Patients were asked the following three questions about their wishes concerning tube feeding:

Have you decided if you want to receive tube feeding if you are no longer able to eat or drink by yourself?

(IF YES) What is your decision? Yes (tube feeding) or No (forgo tube feeding)?

(IF NO) Who would you want to discuss this question with before making up your mind? (possible choices:
physician, hospice nurse, caregiver, family member or friend, no one)

Family members were asked the following three questions about their wishes concerning tube feeding:

Do you think that you would want to receive tube feeding if you became seriously ill and were no longer able to eat or drink by yourself?

Do you know if the patient has decided whether or not he/she wishes to receive tube feeding if he/she becomes unable to eat and drink by him/herself?

(If yes) Do you agree with his/her decision?

Responses to questions were divided into five categories: perceptions; knowledge and experience; attitudes; desires and decisions; and reactions. Answers to all questions were tallied for patient and family member subjects. No elaborate statistical analysis was performed because of the small number of subjects, and because of the nature of the information gathered. The comments made by the subjects were revealing and informative, and provided as much useful information as the answers to the questions. Thus, this study is basically qualitative in nature.

Appendices F, G, and H contain the forms used for this study: Voluntary Informed Consent, Questionnaire for Patients; and Questionnaire for Caregivers/Family Members/Friends.
RESULTS

Interviews were conducted with 14 hospice patients and 18 family members, including a friend. Patient subjects were 7 males and 7 females, ranging in age from 59 to 83 years old (mean = 73.3 years). The patients had different cancers: 3 colon, 2 liver, 2 lung, 2 breast, 1 abdomen, 1 prostate, 1 esophagus, 1 mouth, and 1 adenocarcinoma. The time from hospice admission to date of the interview varied from 1 to 681 days. Seven of the 14 patients had completed less than 8 years of school; 3 attended or completed high school; and 4 attended or completed college.

Family member subjects were 6 males and 12 females, ranging in age from 22 to 79 years old (mean = 58.0 years). The time from hospice admission of the patient to whom they were related to date of the interview varied from 1 to 681 days. Two of the subjects had completed less than 8 years of school; 11 attended or completed high school; and 5 attended or completed college. Overall, family member subjects were younger and better-educated than patient subjects.

Tables 1 and 2 list characteristics of the patient subjects and the family member subjects, respectively, including relationships to each other. Tables 3 through 7 list the number of responses to each question given by patients and family members.

Perceptions:

Table 3 lists the number of responses given by patients and family members about their perceptions of the patients' eating habits, of death in general, and of their
own religiosity or spirituality. Nine patients mentioned that they were eating much less, or very different foods, than they ate before they became ill. Five patients thought that they were eating basically the same as they had before their illness. Two of the patients who thought they were eating the same, JJ and GM, had two family members each who did not agree with that perception.

Fifteen of the 18 family members thought that their patient relative was eating much less or different foods. The remaining three family members were related to AJ, and agreed with her perception that she was eating the same amounts and kinds of foods as she had before her illness.

Five of the 9 patients who said they were eating differently were troubled by these changes in eating, while 4 were not. Ten of the 15 family members who felt that the patient was eating differently were concerned and 5 were not.

Nine of the patients thought that it was normal for a person to stop eating and drinking as death approaches. Two patients, RM and MW, did not agree, and 3 patients did not know. In contrast, 17 of the 18 family members thought that it was normal for a dying person to stop eating and drinking. Only one family member, LS, said that she did not know. LS was the wife of a patient who had been living almost exclusively on formula delivered through a gastrostomy tube (G-tube) for about 28 months. None of the subjects thought that a person who dies without tube feeding feels severe hunger or thirst. Seven patients and 15 family members felt that dying persons did not feel hunger and thirst, while 7 patients and 3 family members did not know. All subjects, except one patient and one family member, considered themselves to be religious or spiritual persons.
Knowledge and Experience:

Table 4 lists the number of responses given by subjects to questions about their knowledge and experience with tube feeding, and their knowledge of patients' rights. Twelve patients and 16 family members were aware of the medical procedures, such as tube feeding, which are available to help feed and hydrate someone who cannot eat and drink by mouth. Two patients and two family members were not aware of these procedures. Nine patients had received some type of tube feeding in the past. Four subjects mentioned having received IV's; two subjects thought they had received IV's at some time; AM with colon cancer had a nasogastric tube (NG tube) temporarily; and AN with esophageal cancer had both an IV and an NG tube temporarily for dysphagia. Thirteen family members had tube feeding in the past; most mentioned having IV's, and two mentioned having tube feeding after gastrointestinal surgery.

Seven patients and 14 family members said that they were aware that there are medical risks associated with tube feeding. Six patients said they were not aware of any risks, while one patient and four family members did not know.

Thirteen of the 14 patients said that they had not discussed with a health professional the use of tube feeding if they became unable to eat or drink by themselves. One patient did not know if he had discussed the issue. Three of the family members had discussed the use of tube feeding for the patient with the physician, the hospice nurse or other hospice worker, and with other family members, but said that no recommendations were made. Thirteen of the patients had not been told what
changes or events to expect if they did or did not receive tube feeding as death approaches. One patient did not know if he had been told. Three family members said that they had been told generally about the signs and symptoms of impending death.

Twelve patients and 17 family members were aware that a patient has the right to refuse any medical treatment, including tube feeding. Eleven patients reported having advance directives, such as living wills or do-not-resuscitate (DNR) orders, while only two family members reported having advance directives. Three patients reported not having advance directives, but signing a DNR order is mandatory for admission to hospice.

**Attitudes:**

Table 5 lists the number of responses given by subjects about their attitudes toward tube feeding. Eight patients thought that it may be permissible to withdraw tube feeding from a patient who is already receiving it. Six patients did not think withdrawal of tube feeding would ever be permissible. These six patients included RM and MW, who were the only two patients who had thought that it was not normal for a person to stop eating and drinking as death approaches. In contrast, 14 of 18 family members thought that withdrawal of tube feeding may be permissible. Three thought that it would not be permissible, including LS, whose husband subsisted on tube feedings. One family member did not know.

Three patients thought that a person must always be given tube feedings if he or she becomes unable to eat and drink, while ten patients did not agree. In contrast, 17
of the family members did not think that tube feeding must always be provided, while one did not know. Of the three patients who thought that a person must always be given tube feedings, JJ said he believed that "if you can't eat, you should get help"; EM believed that no one should "be starved to death"; and RM did not give any reasons for her belief.

Ten patients thought that there are circumstances in which it would be permissible to withhold tube feeding, while three patients, JJ, RM, and MW, did not agree. Patient DL, who had been admitted to hospice the previous day, said he did not know. In contrast, 17 of 18 family member subjects thought that there are circumstances in which tube feeding could be withheld from a patient. The subject who disagreed was HR, whose husband had died in the hospital two years previously, with all life support removed except for IV's.

Desires and Decisions:

Table 6 lists the number of responses given by subjects about their wishes and decisions about tube feeding for themselves. Nine patients had decided if they wanted to receive tube feeding if they became unable to eat and drink, while two had not decided, and three did not know. Of the nine who had made a decision, three patients, JJ, GM, and RM, had decided that they wished to be artificially fed. The remaining six patients, included five females, decided to forgo tube feeding. In contrast, only one family member, LS, thought that she might wish to receive tube feeding if she became seriously ill and unable to eat and drink by herself. Nine other family members
would forgo tube feeding, and eight did not know. Two patients had not decided about receiving tube feeding. One patient, WE, said that there was no one with whom he would want to discuss this issue. The other patient, DL, had been admitted to hospice the previous day, and said that he would want to discuss the issue with his wife before making a decision.

Eight family members knew what the patient had decided about receiving tube feeding. Six of the 8 agreed with the patient's decision, and two did not. JJ's son and GM's wife did not agree with those patients' decision to be fed artificially. JJ's wife said that she agreed with his decision, but erroneously believed that JJ wished to forgo tube feeding.

Reactions:

The final interview question asked subjects how the interview had made them feel. The number of responses given by the subjects is listed in Table 7. Two patients and five family members said that they felt good, while two patients and one family member felt uncomfortable. The majority of subjects, eight patients and ten family members, felt neither good nor bad about the interview. Two patients added that the talk had made them "thoughtful" and "comfortable". Four family members said that they had learned something, and one said that the interview made her think.
Circumstances for Withholding Tube Feeding:

One interview question asked subjects if they thought that there are any circumstances in which it would be permissible to "not give" tube feeding to a patient. It was felt that more information about withholding tube feeding should be solicited from the subjects since decisions about withholding, rather than withdrawing, life-sustaining technologies are more likely to occur with hospice patients. Ten patients and 17 family members answered in the affirmative, and were then asked if they could think of any circumstances. Some subjects provided spontaneous answers. Sometimes, a subject would mention a circumstance or an opinion while answering another question. In such cases, the subject was asked to confirm his or her statement, and this was considered to be another circumstance in which withholding tube feeding might be permissible. The questionnaire contained a list of possible circumstances which often appear in the literature, but these were not discussed with the subjects, and were included only for the convenience of the interviewer.

Table 8 contains a list of possible circumstances in which subjects thought that withholding tube feeding might be permissible, and the number of subjects who mentioned the item. The circumstances are divided into six categories: patient autonomy, physical condition, mental/emotional factors, time factor, prognosis-related factors, and quality of life issues.

Without prompting from the interviewer, subjects provided a variety of circumstances in which they felt that withholding tube feeding might be permissible for a patient. The three circumstances most often mentioned by
patients were: if the patient had chosen to have tube
feeding withheld (n = 4); if the patient had a terminal
illness and would not get better (n = 4); and if the tube
feeding was only prolonging the process of dying (n = 3).
Family members mentioned four circumstances most often: if
the patient had a terminal illness (n = 13); if tube
feeding was prolonging the dying process (n = 7); if the
patient was unconscious, unaware, or in a coma (n = 7); and
if the patient had chosen to withhold tube feeding (n = 7).
Thus, patients and their family members were in agreement
that it would be permissible to withhold tube feeding in
circumstances related to poor prognosis and patient
autonomy.

Comments About Tube Feeding:

Before the interview began, subjects were encouraged
to ask questions or provide comments whenever they wished.
Also, at the end of the interview, subjects were asked if
they had any comments or opinions they wished to add about
the issue of tube feeding for seriously and terminally ill
patients. Many patients and family members were willing to
share their stories and thoughts, and seemed happy to do
so. It is felt that these comments which were given
spontaneously are important to consider when attempting to
determine the opinions of hospice patients and their family
members about providing artificial nutrition and hydration.
Also, because the number of subjects who were interviewed
was small, their comments provide more information.

Subjects were asked if they wished to receive tube
feeding if they become unable to eat and drink normally.
One patient, AN, and five family members said that they
would accept tube feeding as a temporary measure only if their condition was expected to improve. Patient AN had received artificial nutrition and hydration in the past when he had become temporarily unable to swallow. He also mentioned that the mouth care he had received after surgery "was very comforting". Patient AM said she would want tube feeding "only if (she was) still conscious and aware". Several patients mentioned reasons why they believed that a patient should always be given tube feeding. JJ stated that "if you can't eat, you should get help". EM stated that tube feeding should be given "for a while", and that health care providers should not "let anyone starve to death". She thought that she might wish to be tube fed temporarily to "take care of a few things". Four family members stated that tube feeding should be given if "there is a possibility of getting well", or a "hope of change", and that prognosis should be considered.

When asked if it were ever permissible to withdraw tube feeding from a patient who is already being artificially fed, patient JJ stated it would not be permissible "unless no longer needed". Patient HW believed that withdrawal is permissible "if the doctor and the patient's kin think it's okay". Patient EM believed that withdrawal would not be permissible because "it leads to starvation", and added that "if fluid helps them live, keep it going". Patient WE stated that "if (artificial feeding) is started, why stop?" LS, whose husband survived with tube feeding, said it would not be permissible "as long as they can live" with artificial feeding, emphasizing that "without tube feeding, (her husband) wouldn't live".

Patients were asked if they had decided if they wished to receive tube feeding, and family members were asked if they thought they would want to receive tube feeding if
they became seriously or terminally ill. Patient HW did not know if he had decided, but said that "if (he were) dead, no measures should be taken". Patient AJ did not want tube feeding and stated that she was "sure" what she wants for herself. Family member LS would want tube feeding for herself since she would "want to live as long as possible", while family member CM stated that she did not believe in tube feeding, and did not want it for herself or her husband, CM, who had decided he wanted artificial feeding.

Two family members worked in the health care industry. TH worked for a home health agency, and felt that "lots of money (is) wasted in medical care", including artificial life support. In his opinion, "the industry is out of control". BM was a nurse's aide in a nursing home, and believed that artificial feeding is "often overdone" and "has lots of side effects". She had seen patients die, and believed that as death approaches, "the body shuts down" and a person does not need to be fed.

Patients and family members often shared stories about relatives who had faced the decision about life support during serious or terminal illness. Patient ER's sister had been in a coma with severe brain damage, and life support had been removed. ER believed this was the correct choice, and that withdrawal of life support is justified if the situation is "hopeless". Patient WE was living with his dying elderly mother who was being tube fed. He stated that he had not decided if he wanted artificial feeding, but during the interview stated that he "would not want it for myself".

Family member HR, sister to patient AJ, described how her husband had died two years previously in a Veterans Administration hospital from several serious conditions.
All life support, except for an IV, were removed, and he lived for two weeks. She stated that "if (tube feeding had been) stopped, he would have starved". HR was the only one of the 18 family members who believed that it was not permissible to withhold tube feeding from any patients. HM, the husband of patient EM, had watched his first wife die of cancer. She had refused food for two days before she died, and he commented that "I think everything was shutting down; I believe that she knew she was dying, so why bother eating?" AM and BM had watched AM's grandmother die after a stroke at the age of 81. The patient had received tube feeding which "made her sick" and caused nausea and vomiting. LM, daughter-in-law to patient GM, said that her family had chosen to withhold life support from her dying father 14 years previously. They "believed it was his wish". Family member AH summed up her family's wishes for their terminally ill mother. She stated that "our goal is comfort, and to keep her pain-free". They wanted the patient "to die with dignity with our family, not in an institution". Her uncle had died "at home, at peace", and she wanted "the same for my mother".

DISCUSSION

The question of whether or not to artificially feed and hydrate a terminally ill patient is very complex, involving medical, legal, social, and ethical issues. Many physicians and ethicists (37-44) now agree that there is no absolute obligation to provide nutrition and hydration to all patients, and that it is ethical to withdraw or withhold artificial feeding from certain patients. Some
conditions when artificial feeding may not be appropriate are: when a patient's condition is irreversible; when death is likely in the near future; if the illness is terminal; if the patient is in pain, severely debilitated, unresponsive, or severely demented; if the patient has poor quality of life; and if artificial feeding is not in accord with the patient's interests or wishes. Many health care professionals who work with terminal and hospice patients point out the advantages of withholding or withdrawing artificial nutrition and hydration, such as decreases in urinary output, vomiting, coughing and congestion, and edema (6,11,26,45-51). However, in current practice, physicians, who generally are trained to preserve life by using any available technology, are often in favor of aggressive nutrition support for terminal and dying patients (12,14,16,22,23,27).

The decision to use life-sustaining medical treatments, including artificial feeding, should be made after determining a patient's condition, interests, wishes, and preferences (2,52-54). This study is an attempt to determine the wishes and preferences of a small sample of older adult cancer patients in home hospice care, and their family members.

Patients and family members sometimes exhibited differences in perceptions about personal matters. Three of the 6 patients whose family members were also interviewed said that they were eating much less food or different foods than they ate before they became ill, and 3 said that they were not. Family members agreed with the three patients who mentioned eating less or different foods, and with one patient, AJ, who mentioned eating the same. But JJ and GM, who stated that they were eating the same, had family members who did not agree, and perceived
that these patients were eating much less food than they had before becoming ill. This difference in perception about amount of food eaten was also reported by Holden (35), who interviewed 14 hospice patients and their respective primary caregivers. When questioned about the patients' food intakes in the previous two days, 12 of the 14 caregivers reported that the patient was not eating much or not eating well. In contrast, patients tended to speak more positively about what they had eaten and were less likely to discuss quantity.

In this study, 10 of the 15 family members who reported that the patient was eating much less or very different foods than before becoming ill, were troubled or concerned about these changes in eating. Holden (35) found similar results, in which 6 of 14 caregivers reported that the patients' anorexia was "of great concern". Also, 12 of 14 caregivers in Holden's study felt that death would result if the patient continued to eat poorly. Results from both studies indicate the importance of, and concern with, the patient's eating, especially for family members. For many people, providing food and fluids symbolizes care and compassion for another person, and families often use food to express their love for, and desire to help, the patient (6,8,9,17,55).

Patient and family members also differed in their perceptions of more general matters. Seventeen of 18 family members, but only 9 of 14 patients, believed that it was normal for a person to stop eating and drinking as death approaches. In contrast, patients and family members exhibited the same perception of the experience of death without tube feeding. None of the subjects thought that a person who dies without receiving tube feeding feels severe hunger and thirst.
One obvious result from this study is that discussion of the issue of tube feeding was not taking place. None of the patients, and only 3 of 18 family members reported having had discussions about using artificial nutrition and hydration when the patient stopped eating and drinking orally. The three family members who reported discussing the issue reported that no recommendations had been made by the health professional. Also, none of the patients, and only three family members reported being told what changes or events to expect if the patient does or does not receive tube feeding as death approaches. Similar results were seen by Lo et al (56) who surveyed 152 outpatients, 97 of whom had cancer. They found that only 6% of the patients had discussed life-sustaining treatment with their physician, but 68% wanted such discussions. Goold et al (57) surveyed 185 geriatric outpatients, and found that only 19 (10%) had had discussions with their physicians about life-sustaining treatment. These patients were older and had worse prognoses as estimated by their physicians. In both of these studies, the authors conclude that discussions about limiting treatment occur rarely.

Another result seen in this study is that many persons do not draw up living wills and other advance directives. Eleven of 14 patients reported having advance directives, and 3 did not know. Admission to hospice requires that all patients have a DNR order, so all 14 patients did have this type of advance directive. In contrast, only 2 of 18 family members reported having any advance directives. Similar results have been reported in other studies. In 1988, the American Medical Association conducted a public opinion survey which found that 56% of the people surveyed had discussed with family their treatment preferences if they were in a coma, but only 15% had a living will (58).
About 20% of persons with AIDS treated in established community settings had a written directive (59). In SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment), 21% of a population of very seriously ill hospital patients was reported to have advance directives (60). In a study with older adults, aged 67 to 91, High (61) found that 90% of participants had heard of living wills, but only 18% had signed one. Roe et al (62) report that of the 59 healthy senior center participants surveyed, 36% of them had executed durable powers of attorney. In the present study, it is surprising that so few of the family members who are dealing directly with decisionmaking about life-sustaining treatment for their relatives, have advance directives for themselves.

Patients and family members had different attitudes about the issues of withholding or withdrawing tube feeding. Two questions related to the issue of withholding tube feeding. When asked if they thought that a person must always be given tube feedings if he/she could no longer eat and drink by him/herself, 3 patients and none of the family members replied affirmatively. Similarly, when asked if they thought that there are any circumstances in which it would be permissible to not give tube feedings to a patient, 3 patients replied negatively, and 17 of 18 family members affirmatively. When subjects were asked if they thought it is ever permissible to stop tube feeding for a patient if he/she is already receiving tube feeding, 6 of the 14 patients, and only 3 of the 18 family members replied negatively. Eight patients and 14 family members thought that in some circumstances, tube feeding could be withdrawn. Generally, it appears that both patients and family members think that withdrawing tube feeding is less permissible than withholding it, and that patients are more
in favor of using aggressive means of nutrition support than are family members.

Nine of the 14 patients had made a decision about whether they wished to receive tube feeding if they became unable to eat and drink by themselves. Three of the 9 wanted tube feeding, while 6 decided to forgo. Similar results were found by Ouslander et al (32) who surveyed 34 volunteers from a senior adult day center and 34 volunteers in long-term care. When presented with a hypothetical vignette, 50% chose to forgo enteral tube feeding, and 50% decided to accept.

Two of the patients who wanted tube feeding had family members who disagreed with this decision, again illustrating that the family members appear to oppose aggressive nutrition support more than the patients. Sonnenblick et al (63) surveyed 108 offspring of 48 terminally ill patients in Israel, and found that a significant majority of offspring requested the continuation of fluid, nutrition, and medication for their parents. The authors attributed this unexpected desire for aggressive nutrition support and other life-sustaining measures among the offspring to their religiousity and closeness to their parents. The authors also pointed out that their results were very different from those obtained in American studies. Luchins and Hanrahan (64) surveyed 1819 physicians and 500 family members of demented relatives and found that both groups favored the least aggressive level of care for end-stage dementia. The authors found that 71% of family members preferred the least aggressive level of care, which excluded tube feeding and focused on comfort and pain control, for their relatives.

When asked if they thought they would want to receive
tube feeding if they became unable to eat and drink by themselves, 9 of 18 family members in the present study replied negatively. Eight family members did not know, but 6 of the 8 indicated that they would not wish to be tube fed if they became unaware or would not improve. Only one family member, LS, whose husband remained alive with tube feeding, answered affirmatively. These results again appear to reflect the trend of family members to oppose aggressive nutrition support, especially for themselves. These results are similar to those of Ouslander et al (32). Although the offspring in their study requested aggressive life-support for their terminally ill parents, when asked what treatment they would want for themselves should they find themselves in an identical medical state, only 10% wished for nutrition support. Also, 37% of the offspring preferred "no treatment" or active euthanasia for themselves.

Subjects were asked if they could think of any circumstances in which it would be permissible to withhold tube feeding from a patient. Both patients and family members most often mentioned the presence of a terminal illness, the prolongation of the dying process, and the patient's choice to forgo as reasons to withhold tube feeding. While the first two choices might imply that subjects were concerned about a person having to experience pain, only two patients and two family members specifically mentioned the presence of severe pain or discomfort as reasons to withhold tube feeding. This result was somewhat surprising, since many authors emphasize how pain is the symptom most feared by dying patients and their families, and is often undertreated (65-69).

It is interesting to note the pattern of responses for some of the subjects. Patient RM was one of two patients
who thought that it was not normal for a person to stop eating and drinking as death approaches. She also did not think it was ever permissible to withhold or withdraw tube feeding. Not surprisingly, RM was one of three patients who had decided she wished to be tube fed. Patient MW held the same opinions as RM, but had decided to forgo tube feeding.

Patient JJ did not know if it was normal for a person to stop eating and drinking as death approaches, but he was opposed to withholding or withdrawing tube feeding under any circumstances. Not surprisingly, he also decided he wished to be tube fed. Patient GM thought it was normal for a person to stop eating and drinking as death approaches, and was opposed to withdrawing tube feeding. However, he believed that tube feeding could be withheld if the patient chose to forgo, and had decided that he wanted to be tube fed. The three patients who had chosen tube feeding were among the older and less educated of the patient subjects.

Family member LS, whose husband subsisted on tube feeding, did not know if it was normal for a person to stop eating and drinking as death approaches. Not surprisingly, LS was opposed to withdrawal of tube feeding, but was not opposed to withholding. Also, LS was the only family member who thought she would want to receive tube feeding if she became unable to eat and drink by herself, and stated that she would "want to live as long as possible".

Considering the importance of feeding and eating to patients and family members, it was a somewhat unexpected result that only two persons, one patient and one family member, used the word "starvation" when referring to withholding and withdrawing tube feeding.

In general, the interview questions met the purpose of
the study. Subjects such as JJ, RM, LS, and GM gave consistent answers and many subjects made insightful comments, indicating that they were able to understand the questions and formulate answers. However, the option of choosing "I don't know" as an answer to several questions may have been misleading. For example, when patients were asked if they had made a decision about tube feeding, and when family members were asked if they knew if the patient had decided, "yes" or "no" options would have sufficed. In such cases, "I don't know" may have been an ambiguous answer. It was unclear if the respondent did not know if he or she, or the patient, had made a decision, or did not know what he or she, or the patient, wanted.

Patient DL and his wife, PL, were interviewed one day after his admission to hospice, and answered "I don't know" to a number of questions. It would probably be more accurate to interview subjects at a later date after they have become more adjusted to the reality of the prognosis and the ways of hospice.

Before the interviews began, the researcher was concerned that perhaps the nature of the survey, the issue being discussed, and the questions themselves might prove to be troublesome or upsetting to subjects. In reality, only two patients and one family member reported feeling "uncomfortable" after the interview. All other subjects reported feeling either neutral or good. Some expressed gratitude that their opinions were being solicited, and overall, it was felt that the response to the interviews was positive.

In this study, it was possible to interview only six patients with whom family members could also be interviewed. Interviewing matching pairs of patients and
family members as Holden (35) had done might enable more or different interpretations to be drawn.

CONCLUSIONS AND IMPLICATIONS

This study was a modest attempt with a small number of subjects to determine the opinions of hospice patients and their family members about artificial feeding and hydration of seriously and terminally ill patients. Decisionmaking about the use of life-sustaining technology is an important issue for such persons who may be faced with having to choose to accept or forgo certain medical treatments for themselves or a relative.

One conclusion which can be drawn from this study is that discussion of the use of tube feeding is needed among hospice patients, family members, and those health professionals who are providing care. Use of all life-sustaining measures, including resuscitation, should be discussed. However, artificial feeding holds a special significance for most people, including patients, family members, and health care professionals, which is related to nurturance, care, and comfort for another human being. Physicians may find an opportunity for discussion when asking patients about advance directives. Hospice nurses are perhaps more likely than physicians to discuss the subject of tube feeding with patients and family members. At some point, the nurse may be asked by the patient about what to expect when the dying process begins. Also, the nurse usually reviews the signs and symptoms of impending death with family members when it appears that the patient is beginning to decline.
A second conclusion which may be drawn from this study is that, in general, the patients were more in favor of the use of aggressive nutrition support than were family members. This may be a result of the patients' being older and less educated, but is probably directly related to the fact that the patients are the ones who are actually facing death. It may be that when a person knows that death will probably occur in the near future, he or she realizes a desire to live as long as possible, especially if they are not in severe pain or discomfort. It is probably easier to be more detached about death when one is not facing that event imminently.

A third conclusion is that perhaps some of the patients were not cognizant or accepting of the hospice philosophy of favoring palliative care over aggressive treatment for terminally ill patients. Three of the 14 patients had decided that they wished to be tube fed, and 3 indicated that they did not have advance directives, although they had signed DNR orders upon admission to hospice. It is possible that when the physician tells the patient of the prognosis and suggests admission to hospice, he or she is not sufficiently explaining the purpose of hospice. Another possibility is that the patient has not comprehended the terminal nature of his or her condition. When being admitted, the patient may not understand the meaning of the DNR order, or of forgoing aggressive treatment. It must be noted, however, that each patient is an individual, with his or her own method of coping with the prognosis and the possibility of death in the near future. The health professional must decide how much and what kind of information to give the patient and/or family member, based on such factors as the degree of denial or acceptance of the terminal nature of the illness, and the
ability to cope with the situation. As the hospice movement expands, and medical technology advances, the issue of palliative care vs. aggressive treatment may become more familiar to both health professionals and the public.
REFERENCES


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### Table 1. Characteristics of patient subjects (n=14), including family member subjects who were also interviewed

<table>
<thead>
<tr>
<th>PATIENT</th>
<th>SEX/AGE (YRS)</th>
<th>EDUC. LEVEL*</th>
<th>CANCER SITE</th>
<th>DAYS IN HOSPICE</th>
<th>FAMILY MEMBER</th>
</tr>
</thead>
<tbody>
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<td>VJ, JJ</td>
</tr>
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<td>colon**</td>
<td>64</td>
<td>CM, LM</td>
</tr>
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<td>50</td>
<td>none</td>
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</tr>
<tr>
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<td>M/66</td>
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<td>lung**</td>
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<td>colon</td>
<td>1</td>
<td>PL</td>
</tr>
<tr>
<td>AN</td>
<td>M/73</td>
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<td>esophagus</td>
<td>264</td>
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<td>colon**</td>
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</tr>
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<td>F/82</td>
<td>2</td>
<td>liver</td>
<td>681</td>
<td>EC, DR, HR</td>
</tr>
<tr>
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<td>lung</td>
<td>65</td>
<td>PM</td>
</tr>
<tr>
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<td>1</td>
<td>breast**</td>
<td>64</td>
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</tr>
<tr>
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<td>F/69</td>
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<td>breast</td>
<td>204</td>
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</tr>
<tr>
<td>EM</td>
<td>F/70</td>
<td>3</td>
<td>adenocarcinoma**</td>
<td>21</td>
<td>HM</td>
</tr>
</tbody>
</table>

* 1 = less than 8 years  
2 = attended or completed high school  
3 = attended or completed college  

** with metastasis
Table 2. Characteristics of family member subjects (n=18), including patient subjects who were also interviewed

<table>
<thead>
<tr>
<th>SUBJECT</th>
<th>SEX/AGE (YRS)</th>
<th>EDUC. LEVEL*</th>
<th>PATIENT SUBJECT</th>
<th>PATIENT DAYS IN HOSPICE</th>
<th>RELATION TO PATIENT</th>
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</thead>
<tbody>
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<td>JJ</td>
<td>71</td>
<td>son</td>
</tr>
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<td>DC</td>
<td>M/56</td>
<td>3</td>
<td>---</td>
<td>109</td>
<td>son</td>
</tr>
<tr>
<td>EC</td>
<td>M/76</td>
<td>1</td>
<td>AJ</td>
<td>681</td>
<td>friend</td>
</tr>
<tr>
<td>TH</td>
<td>M/43</td>
<td>3</td>
<td>---</td>
<td>42</td>
<td>son-in-law</td>
</tr>
<tr>
<td>HA**</td>
<td>M/77</td>
<td>1</td>
<td>---</td>
<td>49</td>
<td>husband</td>
</tr>
<tr>
<td>HM**</td>
<td>M/70</td>
<td>3</td>
<td>EM</td>
<td>21</td>
<td>husband</td>
</tr>
<tr>
<td>LS**</td>
<td>F/78</td>
<td>2</td>
<td>---</td>
<td>321</td>
<td>wife</td>
</tr>
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<td>F/68</td>
<td>2</td>
<td>GM</td>
<td>64</td>
<td>wife</td>
</tr>
<tr>
<td>BC**</td>
<td>F/56</td>
<td>3</td>
<td>---</td>
<td>109</td>
<td>daughter-in-law</td>
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<tr>
<td>MM**</td>
<td>F/44</td>
<td>2</td>
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<td>daughter</td>
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<td>---</td>
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<td>grand-daughter</td>
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<td>PM**</td>
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<td>RM</td>
<td>65</td>
<td>daughter</td>
</tr>
<tr>
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<td>F/79</td>
<td>2</td>
<td>JJ</td>
<td>71</td>
<td>wife</td>
</tr>
<tr>
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<td>F/51</td>
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<td>2</td>
<td>---</td>
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<td>daughter</td>
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</table>

* 1 = less than 8 years  
2 = attended or completed high school  
3 = attended or completed college

** primary caregiver for patient
**Table 3.** Number of responses to questions about perceptions from patient subjects and family member subjects

<table>
<thead>
<tr>
<th>Category</th>
<th>Patient subjects (n=14)</th>
<th>Family subjects (n=18)</th>
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</thead>
<tbody>
<tr>
<td><strong>Perceptions of Eating:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient eats much less or very different foods than before illness</td>
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<td></td>
</tr>
<tr>
<td>YES</td>
<td>9</td>
<td>15</td>
</tr>
<tr>
<td>NO</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Subject is troubled by these changes in eating patterns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
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<td>4</td>
<td>5</td>
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<tr>
<td>N/A*</td>
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<td>3</td>
</tr>
<tr>
<td><strong>Perceptions of Death:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subject believes that it is normal to stop eating and drinking as death approaches</td>
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<td></td>
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<tr>
<td>YES</td>
<td>9</td>
<td>17</td>
</tr>
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<td>2</td>
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</tr>
<tr>
<td>DON'T KNOW</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Subject thinks that a person who dies without tube feeding feels hunger and thirst</td>
<td></td>
<td></td>
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<tr>
<td>YES</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>NO</td>
<td>7</td>
<td>15</td>
</tr>
<tr>
<td>DON'T KNOW</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td><strong>Perceptions of Self:</strong></td>
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<td></td>
</tr>
<tr>
<td>Subject considers him/herself to be a religious or spiritual person</td>
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<td></td>
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<tr>
<td>YES</td>
<td>13</td>
<td>17</td>
</tr>
<tr>
<td>NO</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

* question was not applicable or no answer was given
**Table 4.** Number of responses to questions about knowledge and experience from patient subjects and family member subjects

<table>
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<tr>
<th>Category</th>
<th>Patient subjects (n=14)</th>
<th>Family subjects (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge/experience with tube feeding:</strong></td>
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<td></td>
</tr>
<tr>
<td>Subject is aware of artificial methods of feeding and hydration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>12</td>
<td>16</td>
</tr>
<tr>
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<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Subject has had tube feeding in the past</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>9</td>
<td>13</td>
</tr>
<tr>
<td>NO</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>DON'T KNOW</td>
<td>2</td>
<td>---</td>
</tr>
<tr>
<td>Subject is aware that there may be risks associated with tube feeding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>NO</td>
<td>6</td>
<td>---</td>
</tr>
<tr>
<td>DON'T KNOW</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Subject has discussed tube feeding for the patient with a health professional</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>---</td>
<td>3</td>
</tr>
<tr>
<td>NO</td>
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<td>14</td>
</tr>
<tr>
<td>DON'T KNOW</td>
<td>1</td>
<td>---</td>
</tr>
<tr>
<td>N/A*</td>
<td>---</td>
<td>1</td>
</tr>
<tr>
<td><strong>With whom tube feeding was discussed</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physician</td>
<td>---</td>
<td>1</td>
</tr>
<tr>
<td>Hospice Nurse</td>
<td>---</td>
<td>2</td>
</tr>
<tr>
<td>Family Member/Caregiver</td>
<td>---</td>
<td>2</td>
</tr>
<tr>
<td>Other Hospice Personnel</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>N/A</td>
<td>14</td>
<td>15</td>
</tr>
<tr>
<td><strong>What did the health professional recommend?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N/A</td>
<td>14</td>
<td>15</td>
</tr>
<tr>
<td>No Recommendation Given</td>
<td>---</td>
<td>3</td>
</tr>
<tr>
<td><strong>Subject was told what to expect if patient does or does not receive tube feeding</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>---</td>
<td>3</td>
</tr>
<tr>
<td>NO</td>
<td>13</td>
<td>15</td>
</tr>
<tr>
<td>DON'T KNOW</td>
<td>1</td>
<td>---</td>
</tr>
<tr>
<td><strong>Knowledge of Patients' Rights:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subject knows that a patient can refuse treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>12</td>
<td>17</td>
</tr>
<tr>
<td>NO</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Subject has living will/advance directives</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>NO</td>
<td>3</td>
<td>16</td>
</tr>
</tbody>
</table>

* question was not applicable or no answer was given

** the number of responses do not add up to 18 for family member subjects since some provided two choices
Table 5. Number of responses to questions about attitudes from patient subjects and family member subjects

<table>
<thead>
<tr>
<th>Category</th>
<th>Patient subjects (n=14)</th>
<th>Family subjects (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Attitudes Toward Tube Feeding</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subject thinks that withdrawing tube feeding may be permissible</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>8</td>
<td>14</td>
</tr>
<tr>
<td>NO</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>DON'T KNOW</td>
<td>---</td>
<td>1</td>
</tr>
<tr>
<td>Subject thinks that a person must always be tube fed if he/she cannot eat and drink</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>3</td>
<td>---</td>
</tr>
<tr>
<td>NO</td>
<td>16</td>
<td>17</td>
</tr>
<tr>
<td>DON'T KNOW</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Subject thinks that withholding tube feeding may be permissible*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>10</td>
<td>17</td>
</tr>
<tr>
<td>NO</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>DON'T KNOW</td>
<td>1</td>
<td>---</td>
</tr>
</tbody>
</table>

* this question included asking subjects about specific circumstances to withhold tube feeding
Table 6. Number of responses to questions about desires and decisions from patient subjects and family member subjects

<table>
<thead>
<tr>
<th>Category</th>
<th>Patient subjects (n=14)</th>
<th>Family subjects (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Desires/Decisions for self/patient:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient has decided about tube feeding for him/herself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>9</td>
<td>---</td>
</tr>
<tr>
<td>NO</td>
<td>2</td>
<td>---</td>
</tr>
<tr>
<td>DON'T KNOW</td>
<td>3</td>
<td>---</td>
</tr>
<tr>
<td>Patient's decision for him/herself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wants tube feeding</td>
<td>3</td>
<td>---</td>
</tr>
<tr>
<td>Will forgo</td>
<td>6</td>
<td>---</td>
</tr>
<tr>
<td>N/A*</td>
<td>5</td>
<td>---</td>
</tr>
<tr>
<td>Family member would want tube feeding for him/herself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>---</td>
<td>1</td>
</tr>
<tr>
<td>NO</td>
<td>---</td>
<td>9</td>
</tr>
<tr>
<td>DON'T KNOW</td>
<td>---</td>
<td>8</td>
</tr>
<tr>
<td>Family member knows patient's decision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>---</td>
<td>8</td>
</tr>
<tr>
<td>NO</td>
<td>---</td>
<td>3</td>
</tr>
<tr>
<td>DON'T KNOW</td>
<td>---</td>
<td>6</td>
</tr>
<tr>
<td>N/A</td>
<td>---</td>
<td>1</td>
</tr>
<tr>
<td>Family member agrees with patient's decision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td>---</td>
<td>6</td>
</tr>
<tr>
<td>NO</td>
<td>---</td>
<td>2</td>
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<tr>
<td>N/A</td>
<td>---</td>
<td>10</td>
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</tbody>
</table>

* question was not applicable or no answer was given
**Table 7.** Number of responses to question about how subjects reacted to the interview

<table>
<thead>
<tr>
<th>Reactions to the Interview:*</th>
<th>Patient subjects (n=14)</th>
<th>Family subjects (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>GOOD</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>NEUTRAL</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>UNCOMFORTABLE</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>OTHER</td>
<td>2</td>
<td>5</td>
</tr>
</tbody>
</table>

*the number of responses do not add up to 18 for family member subjects since some provided two choices*
Table 8. Circumstances for withholding tube feeding and number of subjects who mentioned each

<table>
<thead>
<tr>
<th>Category / Circumstance</th>
<th>Patient Subject</th>
<th>Family Subject</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient Autonomy:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient choice</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Patient dignity</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Physical Condition:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Old age</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Severe pain or discomfort</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Mental/Emotional Factors:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient is burden to family</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>In coma, unconscious, unaware</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td><strong>Time Factor:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long duration of tube feeding</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td><strong>Prognosis-related:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Terminal illness</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>Prolongs dying process</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td><strong>Quality of Life Issues:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor quality of life</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Burdens outweigh benefits</td>
<td>2</td>
<td>3</td>
</tr>
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</table>
JOURNAL ARTICLE #3

Withholding Tube Feeding From Terminal Patients:
Case Studies on the Quality of Death

ABSTRACT

The use of artificial means of nutrition and hydration for dying patients is a controversial issue. Most authors who work with terminally ill patients believe that it may be more beneficial to withhold or withdraw tube feeding, and that terminal starvation and dehydration may have palliative effects. It is also believed that in some cases, the use of intravenous (IV) fluids may result in an increased awareness and sense of well-being for the patient.

The purpose of this study was to investigate the quality of death for five older adult cancer patients in home hospice care who did not receive tube feeding during the dying process. After a patient's death, their hospice medical records were examined, and interviews were conducted with the hospice nurse or family member(s) who had attended the death. The data are presented in the form of five case studies.

Results indicated that most of the patients experienced no anxiety or restlessness, no nausea or vomiting, and no additional pulmonary problems during the dying process. Although 4 of the 5 patients had stopped eating 3 to 7 days before death, they did not seem to exhibit hunger or thirst during this time. For 4 of the patients, pain was either absent or under control. All
five patients were reported to have died peacefully. These five case studies seem to support the position that patients who die without tube feeding do not suffer pain or discomfort, and may experience relief from some troublesome symptoms. Tube feeding has been reported to be beneficial for some patients, but in general, artificial means of nutrition and hydration should not be used routinely with terminally ill patients.

INTRODUCTION

Many terminally ill patients, and patients with cancer, will exhibit anorexia, cachexia, and malnutrition for a variety of reasons, and may have very poor intakes of food and fluids. Such patients can be considered starved, malnourished, or dehydrated, and some health professionals may favor the use of artificial nutrition and hydration, even for the dying patient. However, the medical consequences of nutritional deprivation in a severely ill patient who is close to death are difficult to judge (1). Also, the assumption that nutrition support will benefit terminal patients has not been clearly established (2,3).

Weakness and diminished food intake, either abrupt or gradual, are common changes as death approaches (4). Several authors (1,2,4-7) believe that the dying patient loses interest in food, and finally is unable to naturally ingest food and water. This is an adaptive process that allows the patient to die with less suffering, and aggressive nutrition support may result in more harm than good. Oral food should not be denied to the dying patient, but simply made available as the patient requests or
tolerates it (5).

The process of dying without artificial feeding is described in the literature. Sullivan (3) states that although a patient is severely debilitated from an underlying illness, death may not come quickly, and survival without food and water can continue for weeks. There are reports of patients surviving without food or water for as long as two weeks (8) and 27 days (9). Patients who are not fed may experience mild euphoria, accompanied by an increased tolerance for pain (3). Schmitz and O'Brien (6) have observed that hospice patients who spontaneously decrease food intake experience decreased nausea, vomiting, and abdominal pain, especially where there is a bowel obstruction, liver disease, or malignant ascites. They emphasize that artificial feeding up until death generally increases patient discomfort.

As the dying process continues, the intake of food is no longer a consideration, and hydration becomes the focus (6). As death approaches, the body's systems operate less and less effectively, and patients gradually lose their desire to drink (10). Yet, in current practice, physicians often provide intravenous (IV) infusions to dying patients in the belief that dehydration and electrolyte imbalance are painful and stressful conditions (7,11,12). In the home setting, families may request hospital admission for a patient who stops eating and drinking, with the belief that IV fluids may postpone death (13). Physicians may also fear that not providing artificial hydration may be interpreted as abandoning the patient or as malpractice (8,11).

Several authors believe that thirst and dry mouth are the only seriously troubling and commonly encountered symptoms in dehydrated terminally ill patients, and that
dehydration does not cause pain and suffering (1,5,14). Other authors (6,15-18) mention benefits to the dying patient who is dehydrated, including decreases in urinary output, incontinence, coughing, congestion, shortness of breath, pain, vomiting, and peripheral and pulmonary edema. Sometimes, administration of IV fluids may be beneficial, resulting in increased alertness, less nausea, and correction of cardiac arrhythmias, but the patient will soon die anyway from the underlying disease (17).

Four articles containing case studies about the use of artificial nutrition and hydration in dying patients were found in the literature (9,19-21). Yan and Bruera (19) describe three cases in which patients were managed with a combination of oral and subcutaneous hydration in the palliative care unit. Hypodermoclysis was given temporarily to the three patients, and one also received an IV and nasogastric (NG) tube. The authors emphasize that these three patients represent carefully selected cases in which rehydration prevented additional distress, and allowed the use of other palliative treatments. Printz (20) mentions three case studies of terminal patients who died without medical hydration. In each case, the patient died more comfortably and did not require pain medication. The author concludes that although medical hydration would probably have prolonged the lives of these three patients, it would not have added to their comfort. Andrews et al (9) present three case reports of hospice patients who did not receive artificial hydration during the dying process. When they entered hospice, all three patients were receiving some form of artificial nutrition support, which was subsequently withdrawn. All three patients experienced palliation of symptoms, and died comfortably. The authors conclude that discontinuing artificial nutrition support
for terminal patients is more beneficial. Watts and Cassel (21) describe one case study in which the patient was given IV fluids and an NG tube. After he pulled these out on several occasions, artificial nutrition support was withdrawn, the patient became more responsive, and he died ten days after IV feeding was stopped.

In this study, the term "tube feeding" is used to describe all enteral and parenteral means of medically feeding and hydrating a patient, and does not include normal oral intake of food and fluids.

PURPOSE

The use of artificial means of nutrition and hydration for certain patients, including the terminally ill, is a controversial issue. In some instances, tube feeding may have a palliative effect, temporarily increasing the patient's well-being. However, in the majority of cases, tube feeding, including the use of IV's for hydration, may cause the dying patient increased discomfort.

The purpose of this research was to examine the quality of death in five older adult cancer patients in home hospice care. The results are presented in the form of five case studies.

SUBJECTS AND METHODOLOGY

Subjects for this study were five patients in a small, non-profit hospice in rural southwest Virginia. All
subjects were older than 60 years of age, had confirmed malignan
t disease, and were medically certified as having a life expectancy of six months or less. Subjects were chosen who were receiving adequate daily care from family member caregivers. Suitable willing subjects were identified by the primary care hospice nurses.

The research was approved by the Institutional Review Board of Virginia Polytechnic Institute and State University for projects involving human subjects.

All five subjects and their family members were approached by the researcher to participate in two other studies which are reported elsewhere. Thus, the researcher had established a relationship with all of the five subjects and/or their family members to facilitate gathering information for these case studies. Also, the researcher felt comfortable that the information given by the persons interviewed was consistent with what was known about the patient before his or her death.

After each of the five subjects died, a history of the illness was obtained by reviewing the patient's hospice records, which also contained records from previous hospitalizations. The primary care nurse or the caregiver(s) were interviewed about the quality of the patient's death. Information was gathered about the last days of the patient's life on a data collection form. If the person interviewed was a caregiver, the purpose of the research was explained, and a voluntary informed consent form was signed. Appendices I and J contain the forms used for this study: Voluntary Informed Consent and Interview on the Quality of Death.

Table 1 lists characteristics of the five subjects and the person(s) who were interviewed about the quality of death.
CASE STUDY #1

MC, an 87 year old female, was diagnosed with cancer of the colon three years before entering hospice. At that time, her colon was resected and she had surgery for a colostomy. Previous surgeries had included a cholecystectomy, hysterectomy, and resection of bilateral ovarian cysts, and she had a history of arteriosclerotic hypertensive cardiovascular disease, diabetes mellitus, and sigmoid diverticulosis. Approximately four months before entering hospice, MC was hospitalized for five weeks with an acute fracture of the femoral neck in the right hip, and received hip replacement surgery. Until that time, she had been able to ambulate alone, but after surgery, she used a walker. The hospital report noted recurrent positive nodes in the left groin, chronic lymphedema of both legs and ankles, and a history of "spells" and falling. Otherwise, she was judged to be alert with good teeth and clear lungs.

Three months later, MC presented at the hospital with a large inguinal mass and metastatic lesions along the left superpubic area, which were ulcerating, draining, and malodorous. The diagnosis was tumor necrosis, due to the progressive spread of metastatic colon cancer with secondary infection. She was also diagnosed with squamous cell cancer of the rectum, and refused chemotherapy and radiation therapy. She exhibited no weight loss, was eating fairly well, and was in no pain. She also had no abdominal distention, nausea, vomiting, fever, chills, or sweating.

Upon admission to hospice, MC was observed to have a two-to-three inch gaping wound in the groin; episodic shortness of breath with angina; some wheezing with chest pain; some dyspnea; and severe edema in the legs. She also
exhibited some loss of appetite, diarrhea, chewing difficulties, and ate six small meals per day of soft foods, and foods which were well-managed with her colostomy.

Her daughter-in-law stated that MC thought that her colostomy was the worse thing that ever happened, and that subsequently, she would not leave the house because of embarrassment. She also cared for her own colostomy until right before her death. After her hospitalization for hip replacement, she vowed she would never again be hospitalized. She was noted to be stoic, opinionated, very religious, having no fear of death, but feared being a burden to her family. Up until her last month of life, MC exhibited no confusion.

The hospice nurse reported that MC denied having pain, refused pain medication, but was observed whimpering. She began to grow weaker, more lethargic, and was sleeping more, and Darvocet was begun about two months after admission to hospice. About one month before her death, MC was experiencing pain in the right side, which was relieved with Darvocet; some vomiting; chest pain and shortness of breath with exertion; increasing confusion; and poor appetite. She was also sleeping 12 to 14 hours per day. About two weeks before her death, administration of morphine was begun.

Five days before her death, MC fell, but was not hurt. She began talking to dead relatives and to Jesus, and said she wanted to "come home". She began to refuse food, and two days later she stopped eating, and just sipped water with her medications. She was growing weaker, more confused and somnolent, was vomiting occasionally, and urinated once per day. On the night before and the morning of her death, she vomited. After that, she no longer
complained of nausea. She was observed to be restless with constantly moving hands until about 30 minutes before death. Breathing became more labored, she needed no extra pain medication, her pulse became erratic, and she died late morning, talking to and recognizing her son and daughter-in-law.

According to her caregivers, MC did not appear anxious as death approached, and pain appeared to decrease. They noted no fluid in her lungs, choking sensations, or agitation, and output of urine and feces gradually declined. The patient did not request food or water during the last week of life, but they believed that she experienced no hunger or thirst. Overall, they described MC's death as "peaceful". She had survived for 124 days in hospice.

CASE STUDY #2

AR, an 88 year old female, was a retired school teacher. About two years previous to hospice admission, she was admitted to the hospital because of decreasing appetite, occasional diarrhea, and increasing fatigue and weakness. She received IV fluids, and was noted to be alert and oriented, with normal vital signs. Colonoscopy revealed adenocarcinoma of the cecum, and a CT scan showed no signs of metastasis to the abdomen. The patient had a history of chronic anemia, hypertension, irregular heart beat, use of aspirin, and no use of alcohol or tobacco. Surgery for colon cancer included a right hemicolectomy with placement of a central venous right subclavian line. Post-operatively, she exhibited a fever of 103 degrees F,
and received total parenteral nutrition (TPN), and a blood transfusion. The patient did not receive chemotherapy or radiation therapy.

One month later, AR was admitted to the hospital for mild nausea and vomiting since the surgery, decreased appetite, fever of 103 degrees F, and general malaise. Ultrasound showed atrophy of the gastric mucosa and some gallstones. Her diagnosis was acute pyelonephritis with dehydration. She received IV fluids, antiemetics, and antibiotics.

Approximately 20 months later, AR was hospitalized for weakness, fatigue, loss of appetite, headache, nausea, fever, cough, and congestion. She was noted to appear alert, cooperative, and uncomfortable. She was given IV fluids, oxygen, and pain medication. A chest x-ray revealed metastatic nodules and pleural fluids, and she was diagnosed with metastases to the lungs and liver, and probably diffuse metastasis in the abdomen. Hospital notes mention a "poor prognosis" of approximately two months, and stated that "care is basically supportive, aggressive measures are not indicated". AR was admitted to hospice.

Upon admission, the nurse noted shortness of breath, which was controlled by oxygen; constipation, occasional severe headache; cough, dyspnea, and wheezing; fatigue and weakness; some dehydration and edema; alertness; and a poor appetite with taste changes. The patient was noted to deny having pain, and began to experience itching, which was relieved with medication. About one month after hospice admission, AR was noted to exhibit some confusion, jaundice, edema, heartburn, nausea and vomiting, and occasional diarrhea. She also coughed up thick sputum, and pain was under control.

Her daughter and son-in-law described AR as very
independent with a positive attitude. She had raised her children alone after the death of her husband many years previously. She still lived alone, but family members took turns staying with her 24 hours per day.

About one month before her death, AR became mostly bedfast. Her intake of food and fluids was very low, and she still experienced occasional nausea, vomiting, and diarrhea. She also reported having dry mouth, pain in her right ear and jaw, and some swelling in her left cheek. The jaundice was more pronounced, and edema had increased in her feet, ankles, and lower legs.

Five days before death, AR stopped eating solid food, and took only sips of water and ice chips. Also, pain began to worsen, and medications were increased until the pain was under control. Her abdomen was the source of much of the pain because of slowed peristalsis and constipation, and disimpaction provided some relief. She experienced mild nausea, which was relieved by medication, and no vomiting. She urinated independently until the day before death, and the volume of urine gradually decreased. She was alert and mildly disoriented until the evening before she died. She went to sleep, and in the early morning, made gurgling sounds while she breathed, which later eased. She continued breathing slowly, and died peacefully in her sleep. She had survived in hospice for 99 days.

The patient exhibited no restlessness or fear immediately prior to death. Her family believed that she had wanted to die two weeks previously, but waited until a visit from her son, who was in denial about the imminence of her death. The family reported that they had observed no hunger or thirst in the patient, and that she sipped water when it was offered. The family was extremely pleased that AR had died in her sleep in her own home.
CASE STUDY #3

LA, a 76 year old female, was first diagnosed with colon cancer approximately 18 months before hospice admission. She received a hemicolectomy, and had several chemotherapy treatments for a liver mass, which were not well-tolerated. She was admitted to the hospital two months before admission to hospice, and presented with a left pleural effusion, persistent cough, and mild dyspnea. LA had a history of hypertension, goiter, and hip surgery, had received cobalt treatments for a tumor fourteen years previously, and did not smoke or drink alcohol. During hospitalization, a large right hepatic metastasis and a left pleural nodule were found. The diagnosis was colorectal metastasis to liver and lung.

Two months later, LA was again admitted to the hospital with atrial flutter, persistent nausea and vomiting, increasing shortness of breath, a persistent dry cough, dehydration, and poor intake of food and fluids. She was noted to be alert and oriented, with low blood pressure which responded to IV fluids. She was given IV antibiotics, medication to relieve nausea and vomiting, and a discharge diet of "no salt added". She was told her condition was "not curable", and was admitted to hospice.

Her nursing assessment noted that she was experiencing weakness and fatigue; shortness of breath; no appetite; some nausea and vomiting; taste changes; and fluid in the lungs. She was also alert and was not bedfast. She was constipated, but her appetite began to increase, edema in her legs began to improve, and she began to sleep better. One month later, it was noted that LA was becoming weaker, coughed until she vomited, and began experiencing some pain in her side. In the month before she died, her appetite
decreased, nausea and vomiting increased, and she began to decline. About ten days before she died, she experienced increasing weakness and shortness of breath, and became bedfast.

About three days before she died, LA stopped eating food, and two days before, she drank some Ensure. On the day before she died, she drank only water. She was semi-comatose, began Cheyne-Stokes respiration, and had a catheter inserted to remove urine. She reported not being in pain, but may have been uncomfortable because of heavy breathing through her mouth. She did not appear to be afraid of death, and exhibited no anxiety or restlessness. She wanted to drink, but did not indicate any hunger. No additional pain medication was needed, and no nausea or vomiting was experienced.

On the evening before she died, she went into a stuporous sleep, and appeared to be sleeping into the early morning. Within two hours, she died at some point in her sleep. Her family reported that she had not moved in her sleep or made any noise all through the night. Her family was relieved that she had died peacefully in her sleep. LA had survived in hospice for 74 days.

CASE STUDY #4

AM was a 63 year old female who was diagnosed with oat cell cancer of the lung, for which she received chemotherapy and radiation therapy. Other than having had a cholecystectomy 14 years previously, the patient was healthy, with a history of smoking. Approximately 20 months after diagnosis, the patient was admitted to hospice.
At admission, it was noted that the patient experienced fatigue and weakness; vertigo; shortness of breath and chest pain; dyspnea; some nausea and constipation; anxiety and nervousness; sour mouth with taste changes; decreased appetite; and collapsed vertebrae that caused pain. She was alert and ambulatory, and had experienced a weight loss of 20 pounds in the previous four months. AM remained relatively stable in hospice care for approximately one year.

Eight months before she died, she began exhibiting increasing weakness and fatigue, occasional nausea and sleeplessness, blood in her sputum, and pain in her hands, feet, back, legs, and abdomen. Her appetite began to decrease, and she experienced increasing pain, shortness of breath, and weakness. Approximately three months before she died, AM reported sleeping "too much", coughing, increasing pain in the chest and back, and occasional nausea. About two months before death, the patient was sleeping 16 to 20 hours per day, was eating very little, had episodes of sweating, and was experiencing increased fatigue, weakness, shortness of breath, and back pain.

About three weeks before death, AM was eating and drinking very little, was extremely short of breath, and had difficulty swallowing, but she was alert and pain was controlled. One week before death, the patient was only drinking small amounts of Ensure and water. She was constipated, very weak, congested, and nauseous, and had occasional apnea. IV morphine was begun for pain, and she was considered to be in "impending death" status.

As the week progressed, AM was occasionally slightly confused and incontinent, and her fingertips, hands, and feet became mottled. Pain would increase, and would be diminished with morphine. She slept constantly, and took
only drops of water on her tongue. On the day before she
died, her pain increased, and morphine was given until pain
relief was achieved right before death. The attending
nurse reported that AM did not fear death, but was frowning
and locked worried. She did not appear to be hungry or
thirsty during the last few days and excreted urine through
a catheter until death. She survived for 624 days in
hospice.

The attending nurse and family thought that AM fought
death until the very end because she wanted to live until
the end of the month to see her grandson return home from
the service. She suddenly stopped breathing, so that death
happened quickly, probably from cardiac arrest. The nurse
believed that her last hour before death was peaceful.

CASE STUDY #5

JJ was an 83 year old male who was admitted to the
hospital for dehydration, confusion, and anemia. He had
been diagnosed with prostate cancer seven months
previously, and had not received chemotherapy or radiation
therapy. The patient had a history of chronic illness
including severe gastroesophageal reflux with a history of
esophageal strictures and dilation; hiatal hernia; chronic
esophagitis; anemia of chronic disease; peptic ulcer
disease; chronic hyperamylasemia; hypertension; chronic
hiccups; an asymptomatic lung mass; and had had a
hernorrhoidectomy. He also had fractured both hips which
were pinned; had a left frozen shoulder; a right peg leg
after amputation; a chronic urinary catheter; and a history
of alcohol abuse. At the time of hospitalization, he had
been experiencing a loss of appetite, nausea, epigastric pain, suprapubic and peroneal discomfort, intermittent confusion, and increasing weakness. He was given IV fluids for dehydration and was found to have pancytopenia of unknown origin with anemia, leukopenia, and thrombocytopenia. A bone marrow biopsy showed no infiltration of cancer. Upon discharge from the hospital, he was told he had very little time left, and was admitted to hospice.

At his admission, the patient reported that he was tired; had occasional nausea, vomiting, dysphagia, and constipation; was short of breath; and had chest pain. He also had some chewing and swallowing difficulties, and ate regular but soft foods. One month after admission, JJ reported occasional cough and bladder spasms; constant itching; and blood in his urine. Two months after admission, the patient was experiencing stomach and bladder pain; nausea which was controlled with medication; poor appetite; and an increase in alertness and a decrease in restlessness. The hospice nurse believed that he was drinking alcohol, and his pain was under control.

During the month before he died, JJ had a very poor intake of food and fluids; nausea; headaches; and increasing shortness of breath and weakness. Although his appetite was generally poor, he ate more than usual on the day before his death. On the evening before his death, his family reported that the patient had "a spell", which the nurse believed was a severe dyspneic episode. When the patient began "making strange noises", his family shook him until he awoke, and he remembered nothing. On the day of his death, JJ ate a good breakfast, and he commented that his appetite was greater than usual. He said he wanted to "go to the hospital to die", but his family disregarded
this request. He ate a good lunch and sat down to rest. After about one and one-half hours, he began to breathe noisily as he had done the previous evening, and suddenly died. His death was easy, and probably from cardiac arrest. He had survived for 71 days in hospice.

On the day of his death, JJ's family reported that he made no complaints of pain; had no nausea or vomiting; had very low urine output; and was fully alert until he died.

DISCUSSION

When reviewing the five case studies, similarities and differences emerge in the symptoms experienced by the patients during the dying process. The figure lists the symptoms reported to be present or absent by the interviewee for each of the patients during the last days of life.

All of the patients exhibited gradually declining intakes of food and fluids, and were reported to have poor appetites. Four of the 5 patients stopped all intake of solid food three to seven days before death, and survived on small sips of Ensure and/or water. These observations agree with those of Schmitz (4), who reports that weakness and diminished intake of food and fluids are common changes as death approaches.

Four of the 5 patients exhibited no signs of anxiety or restlessness during the dying process. It was believed that AM was restless because of poor pain control until right before her death, and because she was fighting death. The absence of anxiety and restlessness while dying is commonly observed, and several authors report that terminal
starvation and dehydration generally decrease the patient's discomfort (4,6,9,20).

Four of the 5 patients experienced no nausea or vomiting as death approached. MC vomited on the evening before and the morning of her death. This absence of nausea and vomiting is reported in the literature, and is attributed to the decrease of fluids in the body during dehydration (6,17,18).

The family members and nurses reported that hunger and thirst appeared to be absent in 4 of the 5 patients. The exception was JJ, who ate more than usual on the day before and the day of his death. The results of this study agree with those of McCann et al (8) who monitored 32 palliative care inpatients to determine the frequency of symptoms of hunger and thirst. Their results indicated that 20 patients (63%) experienced no hunger, and eleven patients (34%) had hunger present only initially, and eventually lost their appetite. Twenty-one patients (66%) experienced thirst only initially in their stay (9 patients) or until death (12 patients). Eleven patients (34%) experienced no thirst during their stay.

None of the patients in this study exhibited increased respiratory problems while dying, such as coughing, gagging, shortness of breath, choking, congestion, or presence of fluid in the lungs. This observation agrees with those of other authors (6,17,18,22) who note a decrease in pulmonary secretions because of the decrease in body fluids from terminal dehydration. Dolan (22) describes a small study with hospice patients concerning the need for tracheal suction to remove fluid and lung congestion as a patient nears death. The researchers found that 12 hospice patients who had renal shutdown 24-48 hours before death died peacefully, and did not need suctioning.
At the same time, 12 patients who had been hospitalized before death, and who also experienced renal shutdown, needed to be suctioned. The only apparent difference found between the two groups of patients was the use of IV therapy in the hospital group.

Pain was controlled in 4 of the 5 patients. The need to continuously increase AM's morphine until right before death was attributed to her desire to fight death. LA and JJ were reported to have had no pain, and the family of MC reported that her pain appeared to decrease as death approached. Two authors (3,15,16) report that dying patients who are not artificially fed or hydrated exhibit an increased tolerance for pain. Proutt (15,16) postulates that ketones produced during caloric deprivation may induce an anesthetic effect, or that pain-relieving substances, possible opioid peptides, are produced in increased quantity when a person is deprived of food and water.

Two patients were sleeping almost continually during the last few days preceding death, while three were alert until death. Schmitz (4) states that patients who are dehydrated and remain alert do not seem greatly disturbed during the dying process. They may note their increased weakness, but generally experience less discomfort than patients who receive hydration. The three patients in this study who remained alert until death exhibited no anxiety or restlessness; no increase in respiratory problems; and pain was absent or under control.

All five patients were described as having died "peacefully" by those who were present. This observation agrees with that of several authors who believe that terminal starvation and dehydration do not cause pain and suffering to the dying patient (1,5,8,9,14,20). A study by Oliver (23) of 22 hospice patients who did not receive tube
feeding showed that 12 had essentially normal electrolyte levels, 5 were uremic, and 5 were both uremic and hypercalcemic. However, all 22 patients died peacefully. In the study by McCann et al (8), all 32 patients died in the comfort care unit. Twenty-seven patients (84%) were considered to have been comfortable during their stay and subsequent death, and 4 patients (13%) were thought to have experienced some discomfort during their stay. These authors conclude that terminal patients experience comfort despite minimal or no intake of food or fluids. Printz (20) mentions three case studies of terminal patients who died peacefully without tube feeding. She concludes that although medical hydration would probably have prolonged their lives, it would not have added to their comfort. In her experience, dying patients who are medically hydrated undergo a prolonged, painful dying process. In contrast, dying patients without medical hydration die peacefully and more comfortably, 3 to 10 days after the last intake of fluid. Andrews et al (9) present three case reports of patients who were admitted to hospice using tube feeding, which was subsequently withdrawn. All three patients experienced a decrease in uncomfortable symptoms, and died peacefully. These authors conclude that in terminal patients, discontinuing tube feeding is more beneficial. Watts and Cassel (21) describe a case study in which the patient had an IV and a nasogastric tube removed. He also improved, and died peacefully ten days later.
CONCLUSIONS AND IMPLICATIONS

As mentioned above, many authors cite examples and experiences which seem to indicate that in most cases, it is beneficial to withheld or withdraw tube feeding from dying patients. Terminal starvation and dehydration do not seem to cause pain and suffering to the dying patient, who may not experience hunger and thirst in spite of the intake of little or no food or fluids. In fact, patients who do not receive tube feeding may experience amelioration of some uncomfortable and troublesome symptoms, including pain. The five case studies reported here seem to support this position.

Zerwekh (17,18) believes that tube feeding may serve no purpose in hospice patients, and if multisystem failure is present, may contribute to needless and avoidable suffering. On the other hand, she mentions that with some patients, the use of IV fluids may result in increased alertness and an overall sense of well-being, with improvement in some symptoms. She states that two questions must be asked before administering IV fluids to the dying patient. First, are the IV fluids prolonging the patient's discomfort and suffering? And, second, are the IV fluids relieving any symptoms?

Yan and Bruera (19) describe three cases in which dying patients in a palliative care unit were managed with a combination of oral and subcutaneous hydration. In all three patients, the temporary administration of tube feeding allowed improvement in the patient's status, including an increase in oral intake. In two of the cases, the patients lived for several months with excellent symptom control. The authors also believe that, in general, tube feeding is inappropriate for dying patients,
but in some cases, improvement may result.

McCamish and Crocker (24) mention the following examples of hospice patients for whom artificial feeding methods may be appropriate: (1) patients who have a feeding tube in place and want it to continue to be used; (2) patients for whom an untimely and uncomfortable death may occur without tube feeding; (3) patients for whom it is important to prolong life so that an important event can occur before the patient dies; (4) patients for whom there is a threat of legal action if the tube is not placed or used when the patient's wishes are not known; and, (5) patients for whom the tube is a source of control or denial.

Koshuta et al (25) outline the policy on artificial nutrition and hydration for the Hospice of Washington (DC). The policy was developed by the hospice team of physician, nurses, aides, social worker, volunteer coordinator, chaplain, counselors, and administrator. The team felt that it was critical that the policy emphasize the importance of input from the patient's family in the decisionmaking process. The team found it difficult to identify the merits of artificial feeding, beyond its symbolic importance for the family, in patients who would almost all die within a month even with tube feeding.

A policy was adopted which neither requires nor bars tube feeding. The care plan for each patient is developed and adjusted in collaboration with the patient, family and friends, and the hospice staff, and is expected to reflect the individual patient's goals, values, and capabilities. The policy states that certain observations must be considered when making a decision about tube feeding, including: first, that dying persons who receive artificial fluids may experience adverse symptoms from fluid overload;
second, hospice patients almost never report feeling hunger or thirst; and, third, because of the symbolic nature of providing food and water, even if tube feeding will not benefit the patient physiologically, it may be important to emphasize the use of sips of liquids, spoon feedings, or low-volume tube feedings to protect the sensitivities of some patients and family members.

A policy similar to that of the Hospice of Washington seems to be the most sensible one for other hospices to adopt. It neither promotes nor denies the use of tube feeding, and respects the patient's autonomy. The policy acknowledges the advantages and disadvantages of tube feeding, which should be discussed with the patient and family members as relevant and appropriate. Rather than assuming that every patient who eats and drinks little or nothing is automatically a candidate for tube feeding, the policy acknowledges that for terminally ill patients, aggressive feeding measures are usually inappropriate.
REFERENCES


Table: Characteristics of patients (n = 5), and the persons who were interviewed about their deaths

<table>
<thead>
<tr>
<th>PATIENT</th>
<th>SEX/AGE</th>
<th>CANCER SITE</th>
<th>DAYS IN HOSPICE</th>
<th>INTERVIEWEE</th>
</tr>
</thead>
<tbody>
<tr>
<td>MC</td>
<td>F/87</td>
<td>colon</td>
<td>124</td>
<td>son and daughter-in law</td>
</tr>
<tr>
<td>AR</td>
<td>F/88</td>
<td>colon</td>
<td>99</td>
<td>nurse</td>
</tr>
<tr>
<td>LA</td>
<td>F/76</td>
<td>colon</td>
<td>74</td>
<td>husband</td>
</tr>
<tr>
<td>AM</td>
<td>F/63</td>
<td>lung</td>
<td>624</td>
<td>nurse</td>
</tr>
<tr>
<td>JJ</td>
<td>M/83</td>
<td>prostate</td>
<td>118</td>
<td>wife, son</td>
</tr>
</tbody>
</table>
Figure: Symptoms experienced by the patients ($n = 5$) during the dying process as reported by family members and hospice nurses

<table>
<thead>
<tr>
<th>Symptom</th>
<th>MC</th>
<th>AR</th>
<th>LA</th>
<th>AM</th>
<th>JJ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stopped eating 3 to 7 days before death</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>No anxiety or restlessness</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>No nausea or vomiting</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>No hunger or thirst</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>No respiratory problems</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Pain under control</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Somnolent until death</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Alert until death</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Died peacefully</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
SUMMARY OF RESEARCH

The underlying theme of the three projects which comprise this dissertation is the appropriateness of using artificial means of nutrition and hydration with terminally ill patients. The subjects chosen to study this issue were older adult cancer patients who were in home hospice care, and their caregivers and family members. The first project attempted to describe what and how much these patients eat and drink by mouth, while living and being cared for at home, even until the time of death. The second project acknowledged the fact that at some point, many terminal patients will stop eating and drinking by mouth as death approaches. At this time, the decision about artificial feeding must be made by the patient and the family members. This project attempted to determine the perceptions, knowledge, attitudes, and desires of the subjects about the use of tube feeding, both in general, and for themselves.

In the third project, five case studies were presented of patients who did not receive tube feeding during the dying process while under hospice care. The symptoms, conditions, and quality of their deaths were examined by interviewing those who were present at each death.

Artificial feeding and hydration is one of the life-sustaining technologies available to keep patients alive almost indefinitely. In fact, it is the only technology which, if withheld or withdrawn from a patient who can no longer eat and drink by mouth, will definitely result in death. Deciding when to use tube feeding with terminally ill patients is an important issue for health care professionals, including physicians, nurses, nutritionists, and dietitians. Food and eating in general are important
issues for patients and family members. Since little actual research has been done with hospice patients and their family members, the projects for this dissertation represent an attempt on a small and limited scale to explore and document several aspects of tube feeding for these patients, with these patients.

Project #1: Dietary Intake of Older Adult Cancer Patients in Hospice

Several interesting findings resulted from this project. First, it was found that some patients can survive for extended periods of time with very low intakes of food and fluids, or with significant loss of body weight. This observation is important for patients, but especially for family members, who expend great effort and energy attempting to feed the patient, and worrying about the amount of food eaten. In every instance in which the researcher interacted with the patients and family members, the subject of food intake and its importance was discussed extensively, indicating everyone's interest and concern about the issues of feeding and eating. Second, for three of four patients, it was observed that food and fluid intake steadily decreased as the patient became closer to death. This appears to support the hospice view that it is normal for a person to stop eating and drinking as body systems fail, and death approaches. To the researcher's knowledge, this observation has never been documented in a quantitative manner in the literature, but is always mentioned anecdotally. Third, the patients were eating whatever foods they wanted to eat, in whatever amounts they
wished, and seemed to thrive on this eating pattern. Since
the patients in this study were from rural Virginia, they
generally ate a typical Southern diet, and were eating the
same foods they had always eaten, as long as unpleasant
symptoms were not experienced.

These observations may hold some significance for
health professionals in general. Contrary to the common
belief that a cancer patient, even a terminally ill cancer
patient, must eat to survive, it appears that this may not
be always true. Caution must be taken when attributing a
patient's death to poor food intake. It may be likely,
rather, that approaching death is causing the poor food
intake. Thus, aggressively feeding a terminal patient is
probably not appropriate, unless there is another
overwhelmingly important reason to do so. For hospice
health professionals, it might be inferred that food and
fluid intake is actually only one of many factors which
enhance patient survival. Since hospice takes a wholistic
view of the patient's care, other factors may be just as
important, such as: the emphasis on palliative care,
especially for pain control; the ability of the patient to
remain at home with family members, rather than be
institutionalized; and the active role the patient is able
to take in making her own decisions about care. The
researcher believes that the observation that some patients
survive well beyond their prognosis of six months or less
strongly illustrates the effectiveness of hospice care.

The results of this study hold several implications
for nutritionists and dietitians, who are taught how to
feed patients with all types of diseases and conditions,
but not how to determine if such feeding is appropriate.
One implication might be that patients know how to eat, and
the nutritionist need only to provide some guidance and
suggestions. Related to this, the nutritionist must consider each patient as an individual, with his ethnic or regional food preferences, allowing the patient to eat whatever he finds palatable, rather than what foods are suggested in the textbooks. The fact that some terminal patients survive extended periods may indicate a need for the dietitian to consider ways to maximize nutrition status, and minimize possible deficiencies, perhaps with the use of supplements, including enteral formulae.

Finally, perhaps the dietitian might consider that a patient's low intake of food and fluids may not be cause for alarm, or sufficient reason to use aggressive means of feeding. Palliative nutrition care implies that feeding does not cause or exacerbate any discomfort or troublesome symptoms in the patient. Perhaps the common emphasis on the necessity of eating, and on the amount of food eaten, must be reevaluated.

Research on the dietary intakes of cancer patients, especially terminal cancer patients, is sorely lacking. Some areas for future investigation include: the possible presence of deficiency states, especially of vitamins, minerals, and protein, in patients with low food intake; the possible use of supplements to enhance a terminal patient's well-being by improving skin condition, decreasing weakness and malaise, or increasing appetite and taste sensation; foods which appear to be preferred and well-tolerated in other groups of terminal patients with other conditions, such as AIDS, and in other regions or belonging to different ethnic groups; the relationship of survival to food intake and degree of weight loss; and differences in food intake among terminal patients in home hospice, institutional hospice, or regular hospital care.
Project #2: Tube Feeding: What Do Hospice Patients and Their Families Want?

Hospice patients and their families are likely to face the decision about using or withholding tube feeding at some point. To the researcher's knowledge, this project is the first attempt which has been made to determine the perceptions, knowledge, attitudes, and desires of hospice patients and their family members about artificial feeding and hydration. Several interesting observations were found.

First, the subject of tube feeding is not being discussed among patients, family members, and health care professionals. There is probably no perfect time to discuss this subject, but at some point, the effort should be made. Food intake is an extremely important and symbolic subject for patients and family members, who may be concerned about a patient's "starving" or "dehydrating" to death. It is unlikely that a patient will begin discussion about life-sustaining technologies, so the health care professional must do so. Family members should also be included. Following from this first observation, was the second finding, that 3 of 14 patients decided they wanted to receive tube feeding when they became unable to eat and drink by themselves. This seems to indicate that some patients may not fully understand the hospice philosophy that does not deny tube feeding in every case, but discourages its use in most cases. Again, communication between health care professional and hospice patient may be lacking.

A third observation was that the patients seemed to be less opposed to the use of tube feeding than were their family members. Several reasons may be that the patients
were older and less educated, that they assumed that all medical means would automatically be used to keep them alive, or that they wished to remain alive as long as possible. Conversely, family members who were interviewed were younger and better educated. They may have been more mistrustful of the medical establishment, more understanding of the implications and disadvantages of the use of aggressive means of life-support, or have developed a fear of living with a serious disease after observing the suffering of the patient.

A fourth observation was that both patients and family members mentioned patient choice and the presence of terminal illness as circumstances when it would be permissible to withhold tube feeding from a patient.

These observations may hold some messages for health care professionals, especially those who work in hospice. More communication is necessary about the use or withholding of tube feeding, and also about the hospice view of the use of life-sustaining measures in general. Also, when helping a patient and her family members make a decision about life-sustaining measures, including tube feeding, patient autonomy must be considered. The appropriateness of treatment depends upon the patient's values, opinions, and wishes. On the other hand, the patient and family members must accept the terminal nature of the illness. They should be told that tube feeding is not curative, and will probably serve only to extend life for a short time, or to prolong the dying process, and that the patient will eventually die of the underlying illness. Also, the tube feeding itself may be a source of pain, discomfort, infection, or other problems.

Again, nutritionists and dietitians who have been taught that feeding patients is of prime importance should
be taught also that aggressive nutrition support is probably not appropriate in terminally ill patients. Also, the nutritionist working in hospice should be involved in the education of the patient and family members about the advantages, disadvantages, and probable outcome of tube feeding.

**Project #3: Withholding Tube Feeding From Terminal Patients: Case Studies on the Quality of Death**

The results seen in this project serve to confirm those reported in similar case studies. The main observations were that dying patients who are not tube fed appear to experience a peaceful death, and that terminal starvation and dehydration do not appear to cause suffering or discomfort.

These observations are in accordance with the general hospice beliefs that it is normal for dying patients to stop eating and drinking as death approaches; that terminal starvation and dehydration are not painful, but rather may even have palliative effects; and that tube feeding for the dying patient is generally not appropriate, and may cause or exacerbate troublesome symptoms. These beliefs are generally not held by the medical establishment, and the hospitalized dying patient is likely to be given aggressive nutrition support when he is no longer able to eat and drink normally.

Again, the results of this project indicate the need for health professionals outside of hospice, including nutritionists and dietitians, to consider that artificial feeding and hydration are not appropriate for every patient.
The results of all three projects perhaps indicate a need for health care professionals to perhaps change the focus of the care they provide to terminal patients. Physicians and nurses are taught to preserve life at all costs, but not how to assess how the patient feels about the quality of his or her life. Nutritionists and dietitians are taught to feed patients, even if artificial means must be used, but not how to evaluate the appropriateness of the feeding. In general, traditional health care emphasizes treating the physical disease and conditions, but this may not be the best approach when working with terminally ill and dying patients.

When cure is no longer possible, palliation should become the main focus of any medical or nutrition care. Emphasis on using technology, such as artificial feeding and hydration, should be secondary to determining a patient's individual wishes, quality of life, and overall well-being. The dying patient has different needs than other ill patients, and tube feeding may not be one of the essential elements of his or her care. Terminal patients may live extended periods on little intake of food and fluids, and may experience the cessation of all intake before experiencing a peaceful death. Tube feeding is probably inappropriate in most cases, and withholding such technology not only respects a patient's autonomy, but is also good nutrition care.
APPENDIX A:

Voluntary Informed Consent: Food and Fluid Intake
VOLUNTARY INFORMED CONSENT

Title of Project: Nutrition and Hydration of Older Adult Cancer Patients in Hospice: Food and Fluid Intake

Principle Investigator: Donna S. Ferrandino, Doctoral Candidate, Virginia Tech, Department of Human Nutrition and Foods; working in cooperation with the New River Valley Hospice

You are invited to participate in a study to determine what and how much food and beverages are eaten and drunk by hospice patients. You will also be asked about nutrition-related symptoms you may be experiencing. The purpose of this research is to determine if certain foods are preferred by patients, and what factors, such as drug use and symptoms, might affect food and fluid intake.

If you choose to participate in this study, you will be asked to complete a food intake record for 24 hours, for two consecutive days, every week. For the days you record food intake, you will be asked to mention any nutrition-related symptoms you may be experiencing. Also, at the beginning of the study, and once per month, the investigator will ask you and your hospice nurse questions about your eating habits, drug use, and symptoms to monitor any changes.

No harm to you is expected to result from these activities. However, you may experience some emotional or psychological distress when answering questions. If you experience any discomfort or stress at any time, please inform Donna or your hospice nurse, who will discuss any problems or concerns with you, or who may refer you to a hospice counselor.

Your participation in this research does not guarantee any benefits to you directly, but will provide more information to researchers and health care professionals about how food and fluid intakes affect older patients.

You may receive a synopsis or summary of this research when it is completed. All information which is gathered, all completed forms, and all discussions will be kept confidential, and will be shared only by the researcher and hospice personnel. No names, and only codes, will be used when analyzing and reporting results.
Your participation is voluntary, and you may withdraw from the study at any time without prejudice. Donna will be available to discuss the study's purpose, objectives, or procedures at any time.

This research project has been approved, as required, by the Institutional Review Board for projects involving human subjects at Virginia Tech and by the Department of Human Nutrition and Foods. Should you have any questions concerning this research, contact Donna Ferrandino (552-7993). Should you have any questions about the conduct of this research, contact Ernest R. Stout, Research Division (231-9359).

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

If I participate, I may withdraw at any time without penalty. I agree to abide by the rules of this project.

_______________________________________  Date:  
Signature of participant

_______________________________________  Date:  
Signature of Witness
APPENDIX B:

Patient Data Sheet
PATIENT DATA SHEET

DATE

PATIENT'S NAME

DIAGNOSIS

DATE OF ENTRY TO HOSPICE

MAJOR SYMPTOMS

MEDICATIONS

BODY WEIGHT HISTORY

GENERAL DESCRIPTION OF PATIENT (ambulatory? activities of daily living? ability to feed self? etc.)

HOUSEHOLD INFORMATION

CAREGIVER INFORMATION

FOOD PREPARATION AND SERVICE INFORMATION

327
RECENT MEDICAL INFORMATION (procedures, hospitalizations, etc.)

HAVE YOU HAD ANY ALLERGIES OR SENSITIVITIES TO ANY FOODS IN THE PAST?

HAVE YOU DEVELOPED ANY ALLERGIES OR SENSITIVITIES TO ANY FOODS SINCE YOU BECAME ILL?

ARE THERE ANY FOODS YOU NOW AVOID SINCE BEING ILL?

ARE THERE ANY FOODS YOU PARTICULARLY LIKE NOW OR FIND EASY TO EAT OR DRINK?

IN GENERAL, HOW IS YOUR APPETITE?

EATING PATTERNS

WHAT KIND OF INSTRUCTIONS/INFORMATION HAVE YOU BEEN GIVEN ABOUT WHAT FOODS AND BEVERAGES TO EAT AND DRINK? ARE YOU FOLLOWING THESE INSTRUCTIONS?

ARE YOU TAKING ANY VITAMIN OR MINERAL SUPPLEMENTS?
APPENDIX C:

Directions for Completing the Two-Day Food Intake Record
DIRECTIONS FOR COMPLETING THE TWO DAY FOOD INTAKE RECORD

1. Record everything you eat or drink, including water, for two consecutive days including one weekend day. For example: record on Friday and Saturday, or on Sunday and Monday. Include snacks, gum, candies, etc., and water taken with medications. Do not include spices. Please complete food intake forms for two days every week.

2. Be specific about what type and, if possible, what brand of food or beverage you consume. For example: milk (2%, skim, or whole), cheese (cheddar, lowfat swiss, American), bread (white, whole wheat, French, biscuit). Indicate how the food was processed and/or prepared. For example: canned peaches in heavy syrup, broiled skinless chicken breast, orange juice from frozen concentrate.

3. If the dish contains more than one ingredient (e.g., spaghetti, casserole, tuna salad), list its single ingredients. For example: sandwich (white bread, ham, American cheese, lettuce, tomato, and mustard).

4. In the amount column, indicate the quantity of food or beverage consumed. Estimate as accurately as possible in cups, teaspoons, tablespoons, ounces, slices (bread). Record in common household measurements. If necessary, use the pictures of foods and beverages provided to help estimate amounts.

5. Eat what you would normally eat. Try not to let the recording of what you eat affect your choices.

6. It is easiest to record the food or beverage consumed as you eat it or immediately after. This will prevent forgetting to record small items such as butter, salad dressing, sugar, condiments, etc.

7. If you take any vitamin or mineral supplements, record the brand name and amount of each you take.

REMEMBER: There are no "right" or "wrong" foods and beverages, and there are no "right" amounts of food and beverages to consume. Just record what, and how much, you actually eat or drink of each food and beverage.

If you have any questions, please call me at any time: Donna Ferrandino 552-7993 (home, Blacksburg)
APPENDIX D:

Diagram for Estimating Portion Sizes
8 oz (1 cup)

4 oz (1/2 cup)

1 tablespoon (3 teaspoons)

1 teaspoon

1 oz cheese or lunch meat

3 oz meat, fish, poultry

1/2 cup fruit, vegetables, beans, or rice

This block = 1 oz cheese or meat
APPENDIX E:

Food Intake Record for One Day
<table>
<thead>
<tr>
<th>NAME</th>
<th>CODE</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE</td>
<td></td>
</tr>
<tr>
<td>DAY OF THE WEEK</td>
<td></td>
</tr>
<tr>
<td>AMOUNT</td>
<td>FOOD OR BEVERAGE</td>
</tr>
</tbody>
</table>

SUPPLEMENTS: record names and amounts

Examples of how to record foods and beverages:
- 1/2 cucumber
- 3 oz. ham
- 1 Tbsp mustard
- 2 cups 2% milk
- 2 slices whole wheat bread
Did you experience any of the following symptoms on this day? Please check any symptoms you felt.

___ nausea
___ vomiting
___ diarrhea
___ constipation
___ not hungry/no appetite
___ sleepy, tired, weak
___ food was not appealing
___ no taste or bad taste sensations
___ odor of food was unappealing
___ teeth or denture problems
___ upset stomach
___ pain
___ mouth problems (sores, dry mouth, etc.)
___ feelings of sadness, depression
___ trouble swallowing, choking
___ trouble breathing
___ feelings of anxiety
___ other; please explain ___________________
APPENDIX F:

Voluntary Informed Consent: Attitudes and Beliefs About Providing Artificial Nutrition and Hydration to Seriously Ill Patients
Title of Project: Nutrition and Hydration of Older Adult Cancer Patients in Hospice: Attitudes and Beliefs About Providing Artificial Nutrition and Hydration to Seriously Ill Patients

Principle Investigator: Donna S. Ferrandino, Doctoral Candidate, Virginia Tech, Department of Human Nutrition and Foods; working in cooperation with the New River Valley Hospice and Good Samaritan Hospice

You are invited to participate in a study to determine the attitudes and beliefs of hospice patients and their caregivers and family members about giving tube feedings to seriously ill patients. If you choose to participate, you will be asked a series of questions by the researcher about your beliefs about artificially feeding seriously ill patients, and what your wishes might be for your own health care.

No harm to you is expected to result from these activities. However, you may experience some emotional or psychological distress when answering questions. If you experience any discomfort or stress at any time, please inform Donna or your hospice nurse, who will discuss any problems or concerns with you, or who may refer you to a hospice counselor.

Your participation in this research does not guarantee any benefits to you directly, but will provide more information to researchers and health care professionals about how patients and their caregivers feel about giving tube feedings to seriously ill patients.

You may receive a synopsis or summary of this research when it is completed. All information which is gathered, all completed forms, and all discussions will be kept confidential, and will be shared only by the researcher and hospice personnel. No names, and only codes, will be used when analyzing and reporting results.

Your participation is voluntary, and you may withdraw from the study at any time without prejudice. Donna will be available to discuss the study's purpose, objectives, or procedures at any time.
This research project has been approved, as required, by the Institutional Review Board for projects involving human subjects at Virginia Tech and by the Department of Human Nutrition and Foods. Should you have any questions concerning this research, contact Donna Ferrandino (552-7993). Should you have any questions about the conduct of this research, contact Ernest R. Stout, Research Division (231-9359).

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

If I participate, I may withdraw at any time without penalty. I agree to abide by the rules of this project.

______________________________  Date:
Signature of participant

______________________________  Date:
Signature of Witness

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APPENDIX G:

Questionnaire for Patient
QUESTIONNAIRE FOR PATIENT

Date:               CODE:

Name:               Gender: M F

Education Level:    Age:

1. less than 8 yrs.
2. 8 - 12 yrs.
3. 12 - 16 yrs.
4. postgraduate

Date of diagnosis or beginning of illness:

Date of entrance to hospice:

Please answer YES, NO, or DON'T KNOW to the following questions:

1. At the present time, are you eating much less food, or very different foods, than you ate before you became ill?
   Y     N     D

2. Are you troubled or concerned about these changes in eating patterns or these eating problems?
   Y     N     D

3. Are you aware of the medical procedures available to help someone get enough food and fluids when he/she is not able to eat and drink enough by themselves?
   Y     N     D

4. Have you ever needed to receive food or fluids using a medical procedure, e.g., after surgery, because you could not eat or drink on your own?
   Y     N     D
5. Have any health professionals, such as your doctor or nurse, talked with you about using tube feedings now or in the future, if you become unable to eat or drink?

   Y   N   D

6. With whom have you discussed the possible use of tube feeding?

   a. doctor
   b. hospice nurse
   c. dietitian
   d. family member/caregiver
   e. other hospice personnel
   f. other hospital personnel
   g. other ______________

7. What did each recommend?

8. Do you think that a person must always be given tube feedings if he/she can no longer eat and drink by him/herself?

   Y   N   D

9. (IF YES) What are some of the reasons you believe this?

   a. personal religious views
   b. personal moral convictions
   c. there is a duty to sustain life/do everything
   d. respect for the wishes of family members
   e. other ______________

10. Are you aware that there are medical risks associated with tube feeding?

    Y   N   D

11. Are you aware that any patient, at any time, has the right to refuse any medical treatment, including tube feeding?

    Y   N   D

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12. Do you think that it is normal for a person to stop eating and drinking when he/she becomes close to death?

Y  N  D

13. Do you think that it is ever permissible to stop tube feeding for a patient if he/she is already receiving tube feeding?

Y  N  D

14. Do you think that there are any circumstances in which it would be permissible to not give tube feedings to a patient?

a. old age  
b. patient's choice  
c. terminal illness  
d. patient in severe pain or discomfort  
e. dementia  
f. tube feeding necessary for long duration  
g. patient has poor QOL  
h. patient is a burden to family  
i. feeding prolongs dying process  
j. patient has no dignity/relies on machines  
k. patient is comatose, unconscious, unaware  
l. other ______________

15. Have you decided if you want to receive tube feeding if you are no longer able to eat or drink by yourself?

Y  N  D

16. (IF YES) What is your decision?  
   Y tube feeding  
   N forego

17. (IF NO)  Who would you want to discuss this question with before making up your mind?

a. doctor  
b. hospice nurse  
c. caregiver  
d. family member(s), friend(s)  
e. no one
18. Have you been told by your doctor, nurse, or other health care provider about what changes or events to expect if you do or do not receive tube feeding as death approaches?
   Y  N  D

19. Do you think that a person who dies without receiving tube feeding feels severe hunger or thirst?
   Y  N  D

20. Have you signed any document, such as a living will or a DNR order, to make your wishes known in case you become unable to make these decisions yourself?
   Y  N  D

21. Do you consider yourself to be a religious or spiritual person?
   Y  N  D

22. How has our talk made you feel?
    a. good
    b. bad
    c. neither good nor bad
    d. anxious
    e. uncomfortable
    f. researcher is insensitive

23. Please add any comments you wish to make.
APPENDIX H:

Questionnaire for Caregiver/Family Member/Friend
QUESTIONNAIRE FOR CAREGIVER/FAMILY MEMBER/FRIEND

Date: 

Name: Gender: M F

Education Level: 

1. less than 8 yrs. 
2. 8 - 12 yrs. 
3. 12 - 16 yrs. 
4. postgraduate

Relationship to patient:

Date of diagnosis or beginning of illness:

Date of entrance to hospice:

Please answer YES, NO, or DON'T KNOW to the following questions:

1. At the present time, is the patient eating much less food, or very different foods, than he/she ate before he/she became ill?

   Y N D

2. Are you troubled or concerned about these changes in eating patterns or these eating problems?

   Y N D

3. Are you aware of the medical procedures available to help someone get enough food and fluids when he/she is not able to eat and drink enough by themselves?

   Y N D

4. Have you ever needed to receive food or fluids using a medical procedure, e.g., after surgery, because you could not eat or drink on your own?

   Y N D
5. Have any health professionals, such as the patient's doctor or nurse, talked with you about using tube feedings now or in the future, if the patient becomes unable to eat or drink?

Y N D

6. With whom have you discussed the possible use of tube feeding?

a. doctor
b. hospice nurse
c. dietitian
d. family member/caregiver
e. other hospice personnel
f. other hospital personnel
g. other ________________

7. What did each recommend?

8. Do you think that a person must always be given tube feedings if he/she can no longer eat and drink by him/herself?

Y N D

9. (IF YES) What are some of the reasons you believe this?

a. personal religious views
b. personal moral convictions
c. there is a duty to sustain life/do everything
d. respect for the wishes of family members
e. other ________________

10. Are you aware that there are medical risks associated with tube feeding?

Y N D

11. Are you aware that any patient, at any time, has the right to refuse any medical treatment, including tube feeding?

Y N D
12. Do you think that it is normal for a person to stop eating and drinking when he/she becomes close to death?
   Y  N  D

13. Do you think that it is ever permissible to stop tube feeding for a patient if he/she is already receiving tube feeding?
   Y  N  D

14. Do you think that there are any circumstances in which it would be permissible to not give tube feedings to a patient?
   a. old age
   b. patient's choice
   c. terminal illness
   d. patient in severe pain or discomfort
   e. dementia
   f. tube feeding necessary for long duration
   g. patient has poor QOL
   h. patient is a burden to family
   i. feeding prolongs dying process
   j. patient has no dignity/relied on machines
   k. patient is comatose, unconscious, unaware
   l. other ________________

15. Do you think that you would want to receive tube feeding if you became seriously ill and were no longer able to eat or drink by yourself?
   Y  N  D

16. Do you know if the patient has decided whether or not he/she wishes to receive tube feeding if he/she becomes unable to eat and drink by him/herself?
   Y  N  D

17. (IF YES) Do you agree with his/her decision?
   Y  N  D
18. Have you been told by the patient's doctor, nurse, or other health care provider about what changes or events to expect if the patient does or does not receive tube feeding as death approaches?

   Y  N  D

19. Do you think that a person who dies without receiving tube feeding feels severe hunger or thirst?

   Y  N  D

20. Have you signed any document, such as a living will or a DNR order, to make your wishes known in case you become unable to make decisions by yourself?

   Y  N  D

21. Do you consider yourself to be a religious or spiritual person?

   Y  N  D

22. How has our talk made you feel?

   a. good
   b. bad
   c. neither good nor bad
   d. anxious
   e. uncomfortable
   f. researcher is insensitive

23. Please add any comments you wish to make.
APPENDIX I:

Voluntary Informed Consent: Quality of Death When Patient Does not Receive Artificial Nutrition and Hydration
VOLUNTARY INFORMED CONSENT

Title of Project: Nutrition and Hydration of Older Adult Cancer Patients in Hospice: Quality of Death When Patient Does Not Receive Artificial Nutrition and Hydration

Principle Investigator: Donna S. Ferrandino, Doctoral Candidate, Virginia Tech, Department of Human Nutrition and Foods; working in cooperation with the New River Valley Hospice

A controversy exists among health care providers about the benefits and risks associated with tube feeding seriously ill patients. A seriously ill patient in a hospital is likely to receive tube feeding when he stops eating and drinking on his own. A hospice patient usually is not given tube feedings.

You are asked to participate as a case study of a patient who does not receive tube feedings when no longer eating and drinking independently. The investigator wishes to gather information about the symptoms and conditions experienced by such patients when death is imminent. The investigator may ask questions of you, your caregiver, or your hospice nurse.

No harm to you is expected to result from these activities. However, you may experience some emotional or psychological distress when answering questions. If you experience any discomfort or stress at any time, please inform Donna or your hospice nurse, who will discuss any problems or concerns with you, or who may refer you to a hospice counselor.

Your participation in this research does not guarantee any benefits to you directly, but will provide more information to researchers and health care professionals about giving tube feedings to seriously ill patients.

You may receive a synopsis or summary of this research when it is completed. All information which is gathered, all completed forms, and all discussions will be kept confidential, and will be shared only by the researcher and hospice personnel. No names, and only codes, will be used when analyzing and reporting results.
Your participation is voluntary, and you may withdraw from the study at any time without prejudice. Donna will be available to discuss the study's purpose, objectives, or procedures at any time.

This research project has been approved, as required, by the Institutional Review Board for projects involving human subjects at Virginia Tech and by the Department of Human Nutrition and Foods. Should you have any questions concerning this research, contact Donna Ferrandino (552-7993). Should you have any questions about the conduct of this research, contact Ernest R. Stout, Research Division (231-9359).

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

If I participate, I may withdraw at any time without penalty. I agree to abide by the rules of this project.

_________________________________________  Date:
Signature of participant

_________________________________________  Date:
Signature of Witness
APPENDIX J:

Interview on Quality of Death
INTERVIEW ON QUALITY OF DEATH

DATE: 

PATIENT'S NAME:

PATIENT'S AGE:

DIAGNOSIS:

DATE OF ENTRANCE TO HOSPICE:

DATE OF DEATH:

WHEN WAS THE PATIENT LAST OBSERVED EATING? DRINKING?

The following are some factors to be discussed about the dying process of the patient. What are some of your observations and perceptions? Did any of the patient's symptoms worsen or improve as dying progressed?

pain/discomfort

restlessness/anxiety

fear of death

nausea, vomiting

shortness of breath
choking sensations

sensations of hunger

sensations of thirst

dryness of skin

volume of body fluids/edema

output of urine

state of unconsciousness/coma

amount of pain control necessary

In general, how would you describe how the patient died? Peacefully? Fitfully?

Please record any comments/observations you feel are related to the quality of the patient's death.
VITA

Donna S. Ferrandino was born April 28, 1949 in New York City. She received her B.A. in chemistry from Hunter College in 1970, and her M.S. in environmental health sciences in 1973 from the Hunter College Institute of Health Sciences. In 1989, she enrolled in the Department of Human Nutrition and Foods at Virginia Tech, and was awarded her Ph.D. in August, 1995. She also received a Certificate in Gerontology.

Through the years, she has been employed as a chemist; food sanitation foreman; college instructor; industrial hygienist; co-owner of a small consulting business; freelance writer and photographer; and graduate assistant. Her hobbies are cooking, weight training, reading all kinds of books and magazines, painting watercolors, and spending time with her three dogs.

[Signature]

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