Chapter 8

Nutritional Support and Hydration

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INTRODUCTION

Nutritional support and hydration are the most controversial of the life-sustaining technologies discussed in this report. Most recent court cases concerning life-sustaining technologies involve nutritional support and hydration, and decisions about withholding or withdrawing these technologies evoke a strong response in many people.

Nutritional support can be provided by either of two methods:

- ***enteral or tube feeding procedures*** in which nutrients and water are infused into the patient's stomach or intestine via tubes, [1] or
- ***parenteral feeding procedures*** that include any method other than enteral but are primarily intravenous procedures in which nutrients and water are infused into the patient's veins via catheters.

For people who are unable to swallow, digest, or absorb adequate amounts of food and fluids taken by mouth, these procedures can be life-sustaining.

Total parenteral nutrition (TPN)-an intravenous procedure that supplies sufficient nutrients to maintain a person's normal weight and growth for a prolonged period—was first demonstrated in the late 1960s, and its use has increased dramatically in the past decade. The use of tube feeding has also increased as a result of improvements in materials and formulas and increased interest in nutritional support in general due to the development of TPN (54).

Without questioning the value of nutritional support procedures in general, this chapter addresses four questions about their use for some elderly people:

- Are they used inappropriately for some terminally ill or severely debilitated elderly people for whom they may simply prolong suffering?
- Are they denied to elderly people who would benefit from them?
- How are decisions made about their use, and what role do the patient and family have in the decisionmaking process?
- What is the quality of nutritional support treatments for elderly patients?

Answers to these questions require a synthesis of information from three perspectives that are described below: 1) the ongoing debate about withholding and withdrawing nutritional support and hydration that has been the province of legal and ethical scholars but increasingly involves health care providers and the public; 2) the medical specialty, clinical nutrition, that is the province of nutritional support specialists-physicians, dietitians, nurses, and pharmacists who provide nutritional support; and 3) the growing field of aging and nutrition that is primarily the province of research clinicians. This chapter draws from all three perspectives as they relate to treatment decisions for elderly people.

[1] **Enteral nutrition is sometimes defined to include oral nutritional supplements, but in this report, the term "enteral" refers only to tube feeding.**

PERSPECTIVES ON NUTRITIONAL SUPPORT AND HYDRATION

The Debate About Withholding and Withdrawing Nutritional Support and Hydration

Although physicians have made decisions about withholding and withdrawing nutritional support and hydration for many years, the legal and ethical issues involved in withholding and withdrawing these procedures have been publicly debated only in the past few years. Several factors may account for this change. Increased use of the procedures has resulted in greater public awareness of the decisionmaking dilemmas they sometimes raise. Since the procedures are covered by Medi-

care and Medicaid for many patients, their increased use has also led to concerns about increased public expenditures. Media coverage of court cases involving nutritional support has also resulted in greater public awareness of decision-making dilemmas. In recent years, there has been increasing debate about withholding and withdrawing other life-sustaining technologies, such as dialysis, resuscitation, and mechanical ventilation, and some people think that the current focus on nutritional support is just the next step in this progression. Finally, it has been suggested that since nutritional support and hydration are the only procedures keeping some comatose and severely debilitated patients alive, the current debate may reflect a realization that stopping them is perhaps the only way to allow these patients to die (42,205).

People tend to have intense and divergent beliefs about the appropriateness of withholding and withdrawing nutritional support and hydration. Some people believe that these procedures should almost never be withheld or withdrawn from any patient. Others believe equally strongly that they can and should be withheld from some terminally ill, comatose, and/or severely debilitated patients. Although such patients are often elderly, the debate about withholding and withdrawing nutritional support and hydration is by no means restricted to elderly people.

One point of disagreement in the debate is whether tube and intravenous nutrition and hydration should be considered medical interventions (like the other life-sustaining technologies discussed in this report) or basic supportive or nursing care. People who consider them medical interventions usually argue that they can be withheld or withdrawn in some cases. People who consider them basic supportive or nursing care often argue that they should be withheld or withdrawn only from patients whose death is imminent or for whom it is not medically possible to provide them.

Another point of disagreement in the debate is whether withholding or withdrawing nutritional support and hydration from a terminally ill or severely debilitated patient is killing or merely allowing the patient to die. Some people argue that since all human beings must have food and water to survive, withholding or withdrawing tube or intravenous nutrition and hydration is tantamount to killing the patient. Others argue that withholding or withdrawing them simply allows death to occur as a result of the patient's underlying illness.

A third point of disagreement concerns patient suffering. Some people emphasize patient suffering caused by malnutrition, starvation, and dehydration.' Others emphasize patient suffering associated with aspects of tube or intravenous feeding procedures (e.g., insertion of the tube or catheter or physical restraints that may be used to keep the patient from pulling it out) and suffering related to the continuation of life for patients with intractable pain, severe disability, or very poor quality of life.

A confounding factor in the debate about withholding and withdrawal is the symbolic nature of nutritional support and hydration. Giving food and water is a fundamental aspect of caring for another person, as reflected in the cultural, religious, and moral traditions of our society and the earliest relationship of parent and child. Failure to provide food and water-even when it requires tube or intravenous procedures—is deeply troubling for many people (45).

For this and other reasons, some ethicists who believe that it is sometimes permissible to withhold or withdraw other life-sustaining interventions are hesitant or opposed to ever withdrawing nutritional support and hydration (42,131,192). Some health care professionals share these attitudes. A study of physicians, nurses, and social workers who care for elderly patients (231) found that, on average, individuals in each profession were more uncomfortable about withholding tube feeding and intravenous hydration than resuscitation, antibiotics, and other life-sustaining treatments.

The debate about withholding and withdrawing nutritional support and hydration is not over. It remains a difficult dilemma with important clin-

'Malnutrition is any disorder of nutrition due to unbalanced or insufficient diet or defective assimilation or utilization of nutrients. Starvation is long, continuous deprivation of food. Dehydration is the loss of body water in excess of intake and may be due to decreased intake or increased loss (25).

ical, legal, ethical, financial, and political aspects. This chapter does not attempt to resolve the debate but rather presents information about the procedures and the factors that affect decisions about their use.

The Perspective of Nutritional Support Specialists

Nutritional support specialists focus on clinical aspects of the procedures. They emphasize the positive, therapeutic, and sometimes life-saving effects of nutritional support and hydration and point out that treatment decisions for most patients do not involve complex legal and ethical considerations. In the view of some nutritional support specialists, the most serious concern about the procedures is not questions about withholding and withdrawal but rather problems that restrict their use, including lack of awareness of their therapeutic potential and limited third-party reimbursement.

The debate about withholding and withdrawal focuses on patients who are terminally ill, comatose, or severely debilitated. In contrast, nutritional support specialists focus primarily on patients who are critically ill or physically unable to swallow, digest, or absorb food or fluids taken by mouth. This difference in focus partially explains differences in attitudes toward the procedures. It is important to note, however, that the two groups of patients are not mutually exclusive, and some patients-e.g., severely debilitated patients who are also critically ill and terminally ill patients who cannot swallow, digest, or absorb food or fluids taken by mouth-can correctly be placed in both groups. In fact, some of the most difficult decisions about nutritional support and hydration concern precisely those patients.

The difficulty of determining which patients are terminally ill—a problem that is noted throughout this report—may be of particular concern in decisions about the use of nutritional support and hydration. Health care providers and others differ in their awareness of the potential therapeutic effects of these procedures. Thus, nutritional support specialists, who are particularly aware of the relationship between disease, nutritional status, and treatment outcome, may sometimes correctly classify patients as critically ill but potentially responsive to treatment, when other health care providers, families, and others may incorrectly believe that the same patients are terminally ill.

The meaning of the term “responsive to treatment” is often unclear in discussions about nutritional support and hydration. While some people consider all patients who are kept alive by nutritional support as responsive to treatment, others say that some comatose, terminally ill, and severely debilitated patients are not responsive to treatment and that their dying has merely been prolonged. Depending on the viewpoint of the observer, therefore, the same patients could be considered either responsive or not responsive to treatment.

Careful use of the terms “responsive to treatment,”” critically ill,”“terminally ill)” “comatose)” and “severely debilitated,” is particularly important, though frequently lacking, in debate about nutritional support and hydration (88,111). The uncertainties involved in defining the terms and classifying individuals in these categories, however, must be recognized.

Special Considerations in the Use of Nutritional Support for Elderly Patients

A large proportion of the people receiving nutritional support and hydration are elderly, but there has been relatively little attention to the special needs of elderly patients. Changes in body composition, metabolism, and nutritional requirements associated with normal aging are documented in a growing volume of research (55,140,213). Yet little is known about adjustments in nutritional formulas or techniques that may be needed for elderly people and possible differences in the efficacy of these procedures for younger v. older people.

Assessment of nutritional status of elderly people may be difficult because many assessment techniques used with younger people rely on physiological characteristics that are affected by aging. Yet nutritional standards for the elderly have not been established. Without agreed upon standards,

it is difficult in some cases to determine whether nutritional support is needed.

Several other problems complicate decisions about nutritional support and hydration for elderly patients. A significant but unspecified number of elderly people on nutritional support are confused. Such patients may be unable to participate in decisionmaking. Moreover, because confused patients often try to pull out feeding tubes or catheters, a decision to use nutritional support may imply that physical restraints will also be required, It is also particularly difficult to determine whether severely confused patients are suffering as a result of treatment or, conversely, lack of treatment.

Some elderly patients who receive nutritional support, including many of the confused individuals described above, are nursing home residents. Treatment decisions for these patients are complicated by the fact that some nursing homes are not adequately staffed to provide the skilled care that nutritional support patients need. Each of these problems is discussed at greater length in this chapter.

DESCRIPTION OF NUTRITIONAL SUPPORT AND HYDRATION

The Need for Nutritional Support and Hydration

People who do not take in adequate amounts of food and fluids will eventually die of malnutrition and dehydration or complications of these conditions. Malnutrition is a disorder caused by inadequate intake of calories, protein, carbohydrates, fats, vitamins, minerals, trace elements, or any combination thereof. The effects of malnutrition depend on its severity and duration and which specific nutrients are lacking. In general, however, the effects include weight loss, listlessness, and depression; decreased ability to resist infection, to recover from illness, and to withstand surgery or other treatments; impaired wound healing; decreased cardiac and respiratory muscle strength, confusion, coma, and eventual death (115,139,143,203).

Dehydration, the loss of body water in excess of intake, is caused by decreased fluid intake or inability to conserve fluids as a result, for example, of renal disease or severe diarrhea. Dehydration results in dry mucous membranes; decreased sweat, saliva, and tears; muscle weakness, rigidity, or tremors; confusion, hallucinations, and delerium; abnormal respiration; coma; and eventual death, Reduced body water also alters the concentration of electrolytes such as sodium and potassium, with severe and sometimes life-threatening consequences (210).

People with a variety of conditions are at risk of malnutrition and dehydration. Although some conditions that cause malnutrition or dehydration occur more often in elderly people than younger people, none is unique to elderly people,

People who are physically unable to swallow, digest, or absorb food and fluids taken by mouth are at obvious risk of malnutrition and dehydration. This group includes:

- people who are comatose;
- people who are physically unable to swallow;
- people who have an obstruction of the gastrointestinal tract;
- people who are unable to eat following gastrointestinal surgery; and
- people with acute or chronic diseases that cause inability to digest or absorb nutrients.

Without tube or intravenous feeding and hydration, such people will become increasingly malnourished and dehydrated. As their immune function is reduced, they may die from infections before death can occur from malnutrition or dehydration.

Critically ill patients who are physically able to swallow, digest, and absorb at least some food and fluids taken by mouth may also be at risk of malnutrition and dehydration. Malnutrition in some critically ill patients is caused by anorexia (decreased appetite) associated with certain diseases, such as cancer. In addition, many acute and chronic diseases and treatments such as surgery increase the body's requirements for nutrients; if intake is not increased correspondingly, malnutrition can develop rapidly (115).

Some people are malnourished and dehydrated prior to becoming critically ill. Their malnutrition and dehydration may be due to physical, psychological, or social factors that affect their eating habits, i.e., poor dental status, decreased mobility, social isolation, confusion, poverty, or depression (53,75,137). Moreover, it is likely though not proven, that nutritional reserve capacity decreases as people age. As a result, elderly people may be more susceptible than younger people to malnutrition when their dietary intake is decreased (115).

Critically ill patients who are malnourished can be given oral nutritional supplements if they are able to swallow, digest, and absorb adequate amounts of food and fluids taken by mouth. If not, such patients require tube or intravenous feeding.

People who are too weak to feed themselves or who have neurological diseases that make them unable or unwilling to feed themselves are also at risk of malnutrition and dehydration. Most of these people can be hand fed. Hand feeding is time-consuming, however, and it has been alleged that some hospitals and nursing homes use tube feeding because sufficient staff time cannot be allocated to hand feeding. The use of tube feeding for this reason is generally frowned on, and there are no data to indicate whether or how often it occurs.

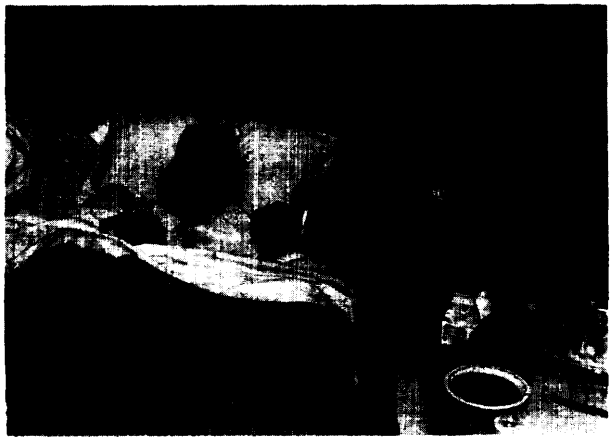


Photo credit: Gretchen Kolsrud

A nursing assistant hand feeds a severely debilitated elderly patient

Some patients cannot be hand fed because they have difficulty swallowing—a condition sometimes associated with stroke and other neurological disorders—and may choke while being fed. Other patients refuse to open their mouths, spit out food, or take in food and fluids so slowly that they cannot be hand fed an adequate diet on a long-term basis, even by a willing and devoted caregiver. The following case illustrates this problem:

Mrs. G had been a picky eater all her life, but 4 months after she was admitted to a nursing home, she stopped eating almost entirely, although she continued to drink small amounts of liquids. Mrs. G had been somewhat confused for several years: she knew her name and recognized regular staff but could not remember their names or where she was. For 2 weeks after she stopped eating, staff sat beside her at meal times, trying to get her to eat something. There had been no observable change in her physical or mental condition. In response to questions, she said that she would eat, that she was not sick or in pain, and that she liked the food. But she did not eat.

Eventually, the doctor ordered nasogastic tube feeding. Mrs. G said she did not like the tube. She turned her head when the nurse tried to put it in, and as a result, she had to be held still by a nursing assistant. Every time the tube was put in, she pulled it out. Her hands were wrapped in gauze, put in thick, quilted mittens, and tied to the bed rails, but she still managed to get the tube out.

Staff continued to try to get her to eat enough so that tube feeding would not be needed. One evening, a nurse sat with her for an hour, during which time she drank 8 oz. of an oral nutritional supplement, about 200 calories, one tiny sip at a time. To take in adequate nutrients, she would have to continue at that rate for at least 8 hours a day—obviously an impossible expectation.

Little is known about elderly people who do not feed themselves and refuse hand feeding or about people who eat too little to live. For the woman in the case just cited, encouragement, supportive listening, and a comprehensive medical examination may provide some clues about a solution to the problem. If that fails, there are only two choices—tube or intravenous feeding against the patient's will or gradually worsening nutritional status and eventual death.

Techniques for Nutritional Support and Hydration

All nutritional support specialists that OTA consulted in the preparation of this report stressed that tube and intravenous procedures are only part of a range of nutritional support options that also includes well-planned meals and oral nutritional supplements. The following discussion focuses on tube and intravenous procedures because they are the subject of clinical, legal, and ethical debate and raise the most difficult treatment questions.

In general, tube feeding is used when the patient's gastrointestinal tract is capable of digesting and absorbing food normally. Intravenous techniques are used when the gastrointestinal tract is blocked or when disease interferes with digestion and absorption of food and fluids.[3] The nutritional support techniques described below are used for patients of all ages. Few adjustments have been made in devices, techniques, or formulas for elderly people. The procedures are described in some detail, because debate about their use often centers on questions about whether they are medical interventions or basic supportive or nursing care and whether their use entails patient suffering.

Tube Feeding Techniques and Associated Risks

Feeding tubes are placed through the patient's nose or a surgical opening into the gastrointestinal tract. Different tube feeding routes are illustrated in figure 8-1. Table 8-1 describes placement procedures, indications for use, and associated risks of each.

Rapid infusion of enteral formulas into the gastrointestinal tract can cause regurgitation, aspiration, vomiting, or diarrhea. Conversely, very slow infusion can result in inadequate nutrition and hydration. In the past, the usual method of infusion was bolus feeding in which the formula is administered in a single dose using a large syringe. For many patients, this method causes diarrhea and other symptoms associated with too rapid infusion (44)176). Another method is gravity drip, in which the formula container is hung above the patient and a regulator clamp controls the flow rate. With gravity drip, hourly monitoring of the flow rate by a nursing attendant, family member, or the patient is necessary (155). Even hourly monitoring may be insufficient, however, since flow rate using the gravity drip method can change by as much as 50 percent in an hour (92).

Enteral feeding pumps assure a uniform infusion rate and lessen the problems associated with too rapid or too slow infusion. Pumps are not always used, however, sometimes because of lack of third-party reimbursement.

Most enteral formulas are bought premixed, although slenderized table food is sometimes used. Premixed formulas vary from those with standard ingredients to those with a defined chemical composition tailored to a specific metabolic disorder. No enteral formulas have been developed specifically for elderly people, although some nutritional support specialists and formula manufacturers are considering developing such formulas (58).

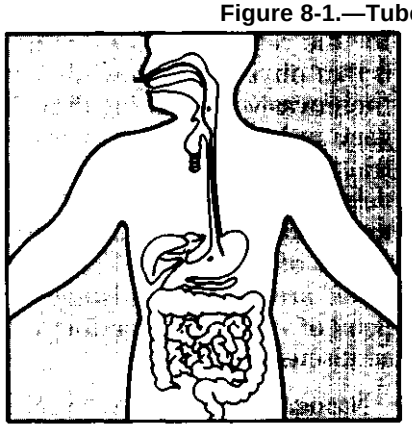
Special formulas for patients with kidney, liver, and respiratory diseases are used for some elderly patients with these diseases. Clinicians disagree, however, about the merits of special formulas (33). Industry representatives have told OTA that some hospitals that were buying special formulas prior to 1983 are now buying more of the standard formulas that are significantly cheaper, probably as a result of cost-containment measures imposed by Medicare and other third-party payers (113).

Recently developed modular formulas allow the combination of individual nutrients to meet the specific needs of each patient and offer an alternative to premixed formulas. Some experts are optimistic about the use of these formulas for critically ill patients (33). Others believe that they will not be widely used because of the staff time required for mixing them and because of the availability of a large variety of premixed formulas (92).

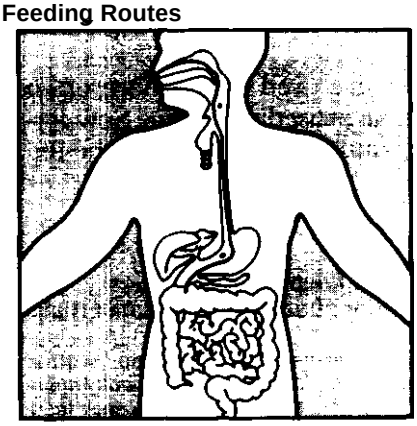
Enteral formulas provide an excellent medium for proliferation of bacteria that can cause diar-

[3] Both tube and intravenous techniques are sometimes referred to as *hyperalimentation*, a term that is not used in this report.

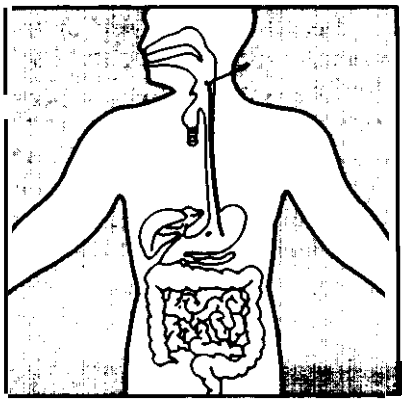
Figure 8-1.—Tube Feeding Routes



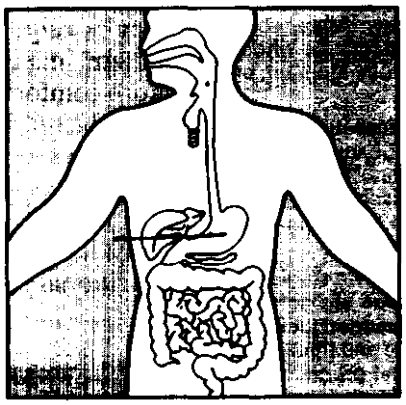
Nasogastric tubes **are placed through the nose, down the esophagus, and into the stomach.**



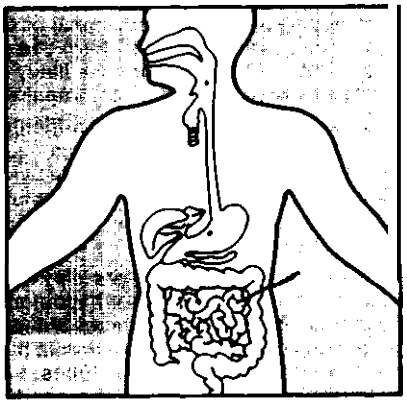
Nasoenteral tubes **are placed through the nose, down the esophagus, through the stomach, and into the duodenum (first loop of the small intestine) or jejunum (second loop of the small intestine).**



Pharyngostomy and esophagostomy tubes **are placed through the neck, into the throat or upper esophagus, and into the stomach.**



Gastrostomy tubes **are placed through the abdomen into the stomach.**



Jejunostomy tubes **are placed through the abdomen into the small intestine.**

SOURCE: Adapted from Ross Laboratories, Tube *Feeding: Clinical Application* (Columbus, Ohio, 1980) reprinted with permission.

rhea, enteritis, and bacteremia (3,15,47,76,183). Enteral infusion times range from 1 to 24 hours a day. If the formula is infused over many hours, special equipment must be used to protect it from airborne contaminants and to keep it cool in order to limit the growth of any organisms (155).

Beyond the Food and Drug Administration's basic "food manufacturing procedure" requirements, there are no Federal regulations for the manufacture or marketing of enteral formulas. The number of companies that manufacture these formulas has increased greatly in the past few years. Claims made for specific formulas by manufacturers are frequently not documented, and there are no regulatory mechanisms to ensure the safety, quality, or suitability of formulas for their intended use, In contrast, infant formulas are highly regulated. Although beyond the scope of this report, a thorough review of the safety and

quality concerns related to these products is needed.

Nasogastric tubes are used much more often than any other enteral procedure, In one New Jersey hospital, for example, 89 percent of tube-fed patients had nasogastric tubes (185). One reason for the relatively wide use of nasogastric tubes is that physicians generally consider such tubes "noninvasive," meaning they do not require surgery and can be inserted by a person with little training. Often in the context of ethical and legal debate, nasogastric tubes are similarly referred to as "noninvasive." In this context, the term noninvasive often seems to suggest that nasogastric tubes are not burdensome. From the patient's point of view, however, they can be burdensome, as discussed below.

Nasogastric tubes are recommended for short-term use. Yet many elderly patients, especially those in nursing homes, are fed through nasogastric tubes for prolonged periods, up to several years. Alternatives to nasogastric tubes for long-term use are pharyngostomy, gastrostomy, and jejunostomy tubes. Although use of these tubes is "invasive" in the sense that at least minimal surgery is required, and each entails risks for the patient, many physicians suggest that they are more comfortable for long-term use than nasogastric tubes and that confused patients are less likely to try to pull them out (39,123,125,129,202). Research is needed to evaluate these alternatives in terms of patient comfort and potential risks, especially for confused patients who need long-term nutritional support.

Table 8-1.-Tube Feeding Techniques: Placement, Indications for Use, and Associated Risks

Nasogastric tubes may be placed by a physician, another health care professional, the patient, or a trained family member. The position of the tube must be tested before each feeding, because the tube can be mistakenly placed in the patient's lungs; if food or fluids are put in the tube while it is in the patient's lungs, severe respiratory distress will occur, potentially causing death. Other risks of nasogastric tube feeding include irritation of the nose, throat, and esophagus, and aspiration, a condition caused by regurgitation of the stomach contents into the lungs.
Nasoenteral *tubes* are usually placed by a physician or a specially trained nurse and must be tested every few days by a trained health care professional or by X-ray. These tubes are recommended for short-term use in patients for whom regurgitation and aspiration are likely or whose stomach or upper intestinal functions are impaired.
Potential problems include the difficulty of passing the tube through the pylorus (the small opening at the lower end of the stomach) and laceration of the pylorus or other parts of the gastrointestinal tract if the tube is removed too rapidly. In addition, feeding into the duodenum and jejunum tends to cause diarrhea.
Pharyngostomy and esophgostomy *tubes* must be surgically placed by a physician. Esophagostomy tubes are seldom used now. Pharyngostomy tubes are recommended for long-term use because they do not irritate the nose and throat like nasogastric and nasoenteral tubes. Potential problems include aspiration, scarring of the insertion site, and swallowing difficulty.
Gastrostomy *tubes* are placed by one of two methods. Surgical placement, that is always by a physician, is done with a local, spinal, or general anesthetic. A newer method, percutaneous endoscopic placement, does not require surgery or general anesthetic. Gastrostomy tubes are recommended for long-term use and when swallowing is impaired as a result of obstruction or neurological disease.
Potential problems include aspiration, skin irritation around the tube site, and displacement of the tube into the abdominal cavity. In addition, the small balloon that is sometimes used to hold the gastrostomy tube in place can obstruct the pylorus and interfere with gastric emptying.
JeJunostomy tubes are surgically placed. These tubes are recommended for long-term use or when there is a problem with gastric emptying or regurgitation. Potential risks include skin irritation around the tube site, clogging, displacement of the tube, and diarrhea.

SOURCE: Adapted from Oley Foundation, "Nutritional Support and Hydration for Critically and Terminally Ill Elderly," prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, November 1985.

Photo credit: Robert B. Gilsldorf, M.D.

For long-term use, a pharyngostomy tube, as shown here, may be more comfortable than a feeding tube that passes through the patient's nose.

The Patient's Experience of Tube Feeding

The patient experience of tube feeding varies greatly depending on the type of tube and the patient's physical and mental condition. Insertion of a nasogastric or nasoenteral tube is uncomfortable for many conscious patients who gag as the tube is put down the throat. For confused patients, insertion of the tube can be frightening and frequently requires that the patient be physically restrained (121)125). Insertion of pharyngostomy, esophagostomy, gastrostomy, and jejunostomy tubes generally requires surgery that is frightening for some patients and entails some postsurgical discomfort.

Nasogastric and nasoenteral tubes can cause irritation of the nose and throat and difficulty swallowing (125,129,137,187,223). Some patients and families object to the appearance of the tube in the nose. However, patients are able to talk, and some can eat or drink small amounts by mouth depending on their physical condition (176). Feeding tubes are generally left in place between feedings, but some patients learn to insert a nasogastric tube themselves, and they may insert and remove it for each feeding.

Many patients who require short-term tube feeding are critically ill and are undergoing concurrent medical treatments, all of which cause varying degrees of discomfort. For them tube feeding may be no more burdensome than the other interventions. Some patients may be so sick that they are only partially aware (if at all) of the feeding tube.

Many elderly patients who receive long-term tube feeding are confused, so it is difficult to determine how they feel about the treatment. Confused patients often try to pull out feeding tubes, especially nasogastric tubes. Some observers believe this behavior indicates that the tube is irritating. Others believe that these patients are too confused to notice the tube and that pulling at it is just restless, meaningless behavior that is characteristic of some confused patients. In many hospitals and nursing homes, patients who pull out their feeding tubes have their hands put in mittens and tied to the sides of their bed or chair to prevent the behavior (118,121,125). Although anecdotal evidence suggests that this practice is widespread, there are no data on the percentage of tube fed patients who are physically restrained.

Intravenous Feeding Techniques and Associated Risks

The most commonly used intravenous feeding techniques are: 1) total parenteral nutrition (TPN), in which a formula capable of maintaining the patient nutritionally for a prolonged period is infused into a vein—usually a large, central vein in the patient's chest; and 2) the well-known intravenous procedure in which water, saline or glucose solutions, and medications are infused into

Photo *credit: Oley Foundation*

This hospital patient who is receiving nasogastric tube feeding is also able to eat small amounts of food normally.

a small, peripheral vein—usually in the patient's arm. The nutrients that can be provided by the latter method are inadequate to sustain life for prolonged periods, although the procedure is frequently used to maintain hydration in critically and terminally ill patients and others. The following discussion refers only to TPN.

TPN catheters are usually placed in large, central veins, because most TPN formulas are highly concentrated and can cause inflammation, occlusion, or clotting in small veins with low blood flow. In high-flow, central veins, the TPN formula is rapidly diluted (72). Figure 8-2 shows a typical TPN placement.

For TPN, a constant and accurate infusion rate is critical, and a variety of pumps are currently available with special features including a battery to ensure that power failure does not interrupt infusion and alarm devices to warn nursing attendants or patients about air in the catheter or occlusions (i.e., resistance to flow that could mean a kink in tubing or a clot) (155).

TPN formulas are individually mixed to match the nutrient and fluid requirements of the patient and modified as the patient's needs change. Laboratory tests are used to monitor the accuracy of the formula. Table 8-2 presents a standard formula. This formula would be modified, for example, for a patient with renal failure to restrict sodium, potassium, magnesium, and phosphorus—minerals whose excretion is defective in renal impairment (155). For most elderly patients, the volume of fluid, 3 liters in table 8-2, should be decreased (50).

TPN patients of all ages are highly susceptible to infection because of malnutrition and acute and chronic diseases. In addition, some TPN formulas provide an ideal growth medium for certain contaminating organisms, and TPN catheters are often left in place for a prolonged period. These factors create a serious risk of catheter-related infection (26,111,155). Some research indicates that such infections occur more often among TPN patients over 60 than those under 60, but one prospective study found no relationship between patient age and incidence of such infections (26,196).

Sterile techniques for mixing the formula, setting up the infusion system, and maintaining the catheter are essential (26,57,111,155). Incidence of catheter-related infections has decreased in the past 15 years because of the use of sterile techniques (61). Nevertheless, these infections have been the primary reason for rehospitalization of patients on TPN at home in each year for which information is available (1979 to 1983) (149,150, 151)152,153),

Other potential complications of TPN are mechanical problems with insertion and maintenance of the catheter and metabolic problems related to the formula. Isolated cases of death due to air entering the veins via a TPN catheter have also been reported (134). For long-term TPN patients, micronutrient deficiencies are frequently a problem (155).

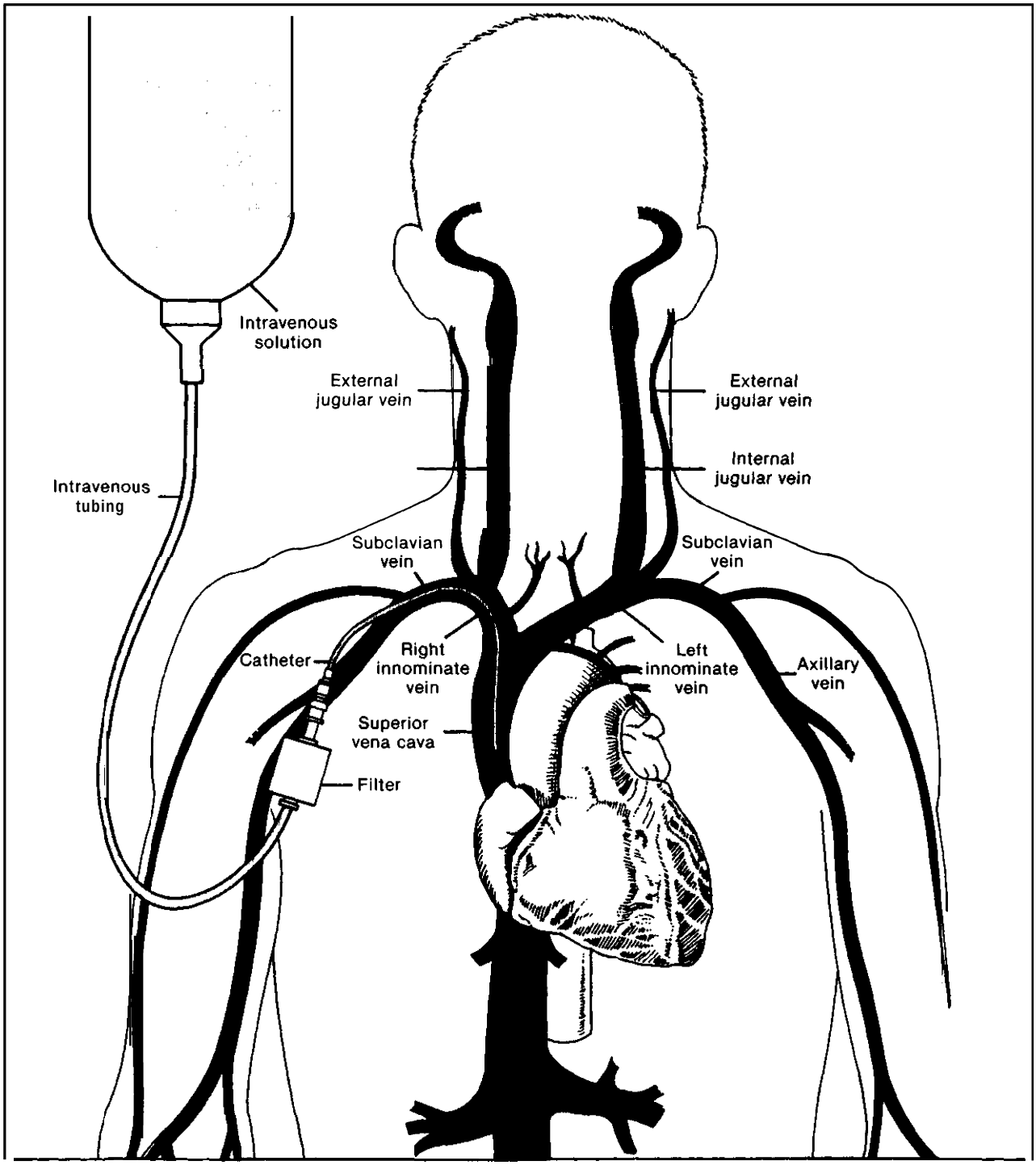
Table 8.2.—Standard TPN Formula (24 hours) for a 70-kg Adult

Fluid ... , ... 3 liters	
Protein (amino acids) . . . . . 0.2 to 0.3 g nitrogen/kg	
Calories[a] **. . . . . 25 to 40 kcal/kg**	
Essential fatty acids (lipids) . . 2°/0 of total **calories**	
Electrolytes:	
Sodium . . . . . 100 mEq	
Potassium . . . . . 100 mEq	
Chloride. . . . . 130 mEq	
Acetate/gluconate . . . . . 90 mEq	
Calcium . . . . . 15 mEq	
Magnesium . . . . . 20 mEq	
Phosphorus . . . . . 300 mg	
Trace Elements[b]**:**	
Zinc . . . . . 5 mg	
Copper. . . . . 1.5 mg	
Iodine . . . . . 120 µg	
Selenium . . . . . 100 µg	
Chromium . . . . . 15 µg	
Manganese . . . . . 2 mg	
Vitamins:	
Ascorbic acid . . . . . 100 mg	
Thiamine . . . . . 3 mg	
Riboflavin . . . . . 3.6 mg	
Niacin . . . . . 40 mg	
Pantothenic acid . . . . . 15 mg	
Pyridoxine. . . . . 4 mg	
Biotin . . . . . 60 µg	
Folic acid . . . . . 400 µg	
Cobalamin. . . . . 5 µg	
Vitamin A . . . . . 4,000 I.U.	
Vitamin D . . . . . 400 I.U.	
Vitamin E . . . . . 15 mg	
Vitamin K . . . . . 200 µg	

[a] **Provided** principally as dextrose.
[b] **Iron** may be added to the formula at 1 to 3 mg per day or **given** by mouth or **intermuscularly**.

SOURCE: Oley Foundation, "Nutritional Support and Hydration for Critically and Terminally Ill Elderly," prepared for the Office of Technology Assessment, U.S. Congress, Washington DC, November 19S5.

Figure 8-2.—A Typical TPN Catheter Placement



Concentrated nutrient solution is infused through a catheter into the superior vena cava, the l-inch vein that returns blood to the heart from the upper part of the body. The catheter is inserted into the right subclavian vein and pushed along until its tip is in the superior vena cava. The catheter can also be inserted through the left subclavian vein or one of the jugular veins (72).

SOURCE: S.J. Dudrick and J.E. Rhoads, "Total Intravenous Feeding, " Scientific *American 226(5):73-8O, 1972.*

In hospitals, metabolic complications including alterations in blood glucose and phosphorus are the most common complication of TPN (230). Although such complications can reflect errors in the TPN formula, they also occur as the patient's metabolism and nutrient requirements change in response to TPN. They can usually be anticipated and minimized with careful monitoring by professionals trained in the use of TPN (57,111,137).

The Patient's Experience of TPN

As it does with tube feeding, the patient's experience of TPN varies depending on his or her general physical and mental condition. Critically ill patients on short-term TPN may be no more bothered by intravenous feeding than by other treatments. Those who require long-term TPN, however, face significant physical and psychological obstacles to acceptance of the treatment. The catheter that remains in the chest can be both annoying and frightening. In addition, patients must cope with the feeling of dependency on the treatment, fears about life-threatening complications, and anxiety about the cost of treatment. Despite these problems, many patients on long-term TPN at home lead active and satisfying lives (155).

Photo credit: Oley Foundation

The TPN catheter that remains in the patient's chest can be both annoying and frightening, but many patients on long-term TPN adjust well to the treatment.

Anecdotal evidence indicates that TPN, unlike tube feeding, is seldom used for long-term treatment of confused patients. When it is used for confused patients who may try to pull out the catheter, physical restraints are necessary because pulling out, disconnecting, or tearing a central venous cathether is dangerous, although not usually life-threatening.

Tube Feeding v. TPN

Tube feeding is often perceived as inexpensive and relatively simple (44,132), whereas TPN is perceived as expensive, "high-tech" medical care that requires the involvement of skilled professionals. This dichotomy obscures important similarities between these procedures. In fact, both procedures are used for acute and long-term treatment, and while TPN is generally more complex and hazardous, tube feeding also entails risks and requires the involvement of skilled professionals, at least for clinically complex patients (90,125).

The primary determinant of which feeding method is used is the patient's physical condition. Nutritional support specialists agree that tube feeding should be used if the patient is capable of digesting and absorbing food and fluids normally; if not, TPN is required. In the vernacular of the field, "If the gut works, use it. " Yet TPN is sometimes used when tube feeding is possible and might be more effective (90)126)170)175)210). This use of TPN may occur because of staff training and preferences or because third-party reimbursement may be easier to obtain for TPN than for tube feeding.

Clinical Research Issues Related to the Use of Nutritional Support and Hydration for Elderly Patients

Although tube and intravenous nutrition and hydration procedures are widely used, many clinical questions about the procedures, particularly their use for elderly patients, remain unanswered. Some of the most important questions are summarized below. Research on each of these questions is needed to improve clinical decisionmaking and quality of care for elderly patients.

Efficacy of Nutritional Support

Tube and intravenous nutritional support and hydration are clearly effective in sustaining life for patients of all ages who are physically unable to swallow, digest, or absorb food and fluids taken by mouth and for patients who do not take in food or fluids for whatever reason. Efficacy has been more difficult to demonstrate for critically ill patients who are physically able to eat but cannot eat enough to maintain normal nutritional status. Nutritional support improves the indices of nutritional status in these patients (116), but efficacy in terms of outcome measures such as mortality, morbidity, or length of hospital stay has been more difficult to demonstrate (14,60,79).

Some nutritional support specialists argue that "there are no illnesses that do better when the patient is starved" and that efficacy has been demonstrated as definitively for nutritional support as for most other medical treatments (9 I). Others believe that efficacy in terms of outcome measures has been established for some diseases but not others, for which it is, nevertheless, frequently used.

Among patients with the same disease, nutritional support may be essential for those who are more severely ill and unnecessary for those who are less severely ill (14). In this case, the difficulty of measuring severity of illness may complicate the process of establishing efficacy.

Clearly, there are some severely ill, malnourished patients who will die even with nutritional support. Predicting outcome is difficult, but one study of patients of all ages in an intensive care unit (48) used APACHE II, a clinical assessment instrument developed to classify severity of illness, to predict outcome in the patients who received TPN. The system predicted death with 10()-percent specificity—that is, all eight TPN patients who were predicted to die in the hospital did die. (Seven other patients who were predicted to live also died in the hospital.) withholding TPN from patients who were predicted to die and then did die would have reduced the annual cost of TPN to the hospital by 28 percent. The researchers conclude:

> The disparity between demand and available health care resources is a universal problem. Political and bureaucratic measures are increasingly being imposed on the medical profession to reduce health care costs. These measures are often viewed by the medical profession as being harmful to patient care and clinical freedom.
>
> One way to improve cost-effectiveness is to examine critically the way we prescribe expensive therapies . . . . By not treating patients who will not benefit, cost-effectiveness is increased, with a simultaneous reduction in the total cost. The ethical problem is to identify these patients accurately (48).

The American Society for Parenteral and Enteral Nutrition recently issued guidelines for use of TPN for hospitalized adult patients (12). These guidelines define conditions for which TPN should be a part of routine care, conditions for which it is usually helpful, conditions for which it is of limited value, and conditions for which it should not be used. The last category includes cases where the patient or legal guardian does not want TPN. No similar guidelines are available for tube feeding.

Several factors suggest that nutritional support might be less effective, on average, for older than younger patients. Physiological changes associated with normal aging might limit the capacity of a patient's body to respond to tube or intravenous feeding. In addition, the greater prevalence of acute and chronic conditions among elderly people might increase the risks of treatment for them, It should by noted, however, that these considerations apply to elderly people as a group, and, because of the heterogeneity of the elderly population, do not apply equally to all elderly persons. Moreover, since many elderly patients with acute and chronic diseases are malnourished, nutritional

support might have a greater positive impact on outcome for elderly patients as a group than for younger patients.

Despite the relevance of these considerations to treatment decisions, OTA is aware of only one study (104) comparing efficacy for older versus younger patients. A comparison of responses to tube and intravenous feeding for 37 patients under age 65 and 65 patients over age 65 found no statistically significant differences between the groups in nutritional status indicators, although the direction of the findings indicated consistently poorer response among elderly patients. Mortality was significantly higher in the older group. More information about the efficacy of nutritional support for older patients is needed to support clinical decisionmaking.

Assessment of Nutritional Status in Elderly People

Determining an individual's need for nutritional support, selecting the appropriate feeding method and formula, monitoring the patient's response to treatment, and determining efficacy require a method for collecting information about a patient's nutritional status and standards with which to compare this information.

Various methods are used to assess nutritional status in individuals of all ages:

- Dietary histories that provide a record of calories, protein, fat, carbohydrates, vitamins, and minerals and sometimes alcohol and drugs consumed by the individual over a designated time period.
- ***Anthropometric measurements*** such as weight and measures of lean body mass and fat stores (e.g., skinfold thickness and arm circumference).
- Biochemical ***measurements*** such as levels of serum albumin and serum transferring.
- ***Hematologic measurements*** that can be used to identify anemia related to lack of specific nutrients.
- ***Measurement of immune responses*** such as total lymphocyte count and cell-mediated immunity.
- ***Measurement of vitamin and mineral status.***

Changes in body composition and metabolism associated with normal aging are known to affect the indices of nutritional status used in these assessment methods. Many of the effects are not fully understood, however, and nutritional standards that take these effects into account have not been developed. The lack of standards makes it difficult to interpret findings for individual elderly patients.

For example, dietary requirements for elderly people are unknown or controversial for many nutrients. On average, caloric needs are reduced in elderly people because of decreased physical activity and decreased metabolic rates associated with smaller lean body mass. It is unclear, however, whether protein requirements are generally increased or decreased in elderly people. Requirements for fats, carbohydrates, and many vitamins and minerals are also unknown. The need for some nutrients may be increased because of reduced absorption of these nutrients associated with normal aging (51,115)142)181).

Recommended Dietary Allowances (RDAs) formulated by the National Research Council are available for the age group 51 +. The use of a single set of RDAs for the age group 51+ fails to account for important physiological differences between people who are under age 60, for example, and people over age 80 or 90. A new edition of the RDAs was scheduled for release in 1985 but has been delayed, partly because of the difficulty of establishing RDAs for elderly people (141, 181).

Anthropometric measures such as fat stores and lean body mass are used to determine nutritional status in patients of all ages, but lack of standards for interpreting findings for elderly patients complicate their use for these patients. For example, skinfold thickness is used as a measure of fat stores, but alterations in fat distribution, skin elasticity, and other characteristics of aging skin make skinfold measurements difficult to interpret after age 60 (34,60,80). Similar problems limit the usefulness for older persons of each of the assessment methods listed above. These problems are discussed further in appendix F.

In addition to being affected by normal aging, nutritional status is affected by acute and chronic diseases, and accurate assessment of a patient's nutritional status requires an understanding of their effects. Many of the diseases that affect nutritional status-e.g., acute and chronic infections, cerebrovascular and cardiovascular disorders, cancer, and chronic renal, pulmonary, and liver diseases-occur in patients of all ages but are more common in elderly people than in younger people. Decreased food and fluid intake is extremely common in patients with many of these diseases. Yet the same diseases often increase nutritional requirements. Gastrointestinal absorptive capacity is also altered by many diseases (115). In addition, treatments that cause nausea or lessen appetite and diagnostic procedures that require the patient to be without food or water for short periods affect nutritional status.

Acute and chronic diseases affect some of the commonly used indices of nutritional status. Cancer, congestive heart failure, and kidney and liver disease, for example, decrease the level of serum albumin, a frequently used biochemical measure of nutritional status, but lower serum albumin levels do not necessarily indicate malnutrition in patients with these diseases. Conversely, dehydration increases the level of serum albumin, but higher serum albumin levels in dehydrated patients may not indicate normal nutritional status (51).

Drug-nutrient interactions are common in elderly patients and must also be considered in assessing nutritional status. Elderly persons with acute and chronic diseases often take large numbers of drugs, some of which interfere with metabolism and can cause specific nutritional deficiencies. Many drugs also cause nausea or a reduction in appetite that can decrease food and fluid intake. Mood altering drugs can cause changes in cognitive function that markedly affect food and fluid intake (115)128)172).

The complexity of the relationship between nutritional status, normal aging, acute and chronic disease, and drug-nutrient interactions suggests that a thorough assessment is needed before treatment is initiated. According to many nutritional support specialists, however, simple, inexpensive assessment procedures can be used to screen people at risk for nutritional deficiencies (56,90)166) 184,210). Loss of 10 percent of usual body weight in 6 months or less is one such screening measure (53). At one hospital, surgical patients who had lost 10 pounds or more in the preceding 6 months were more likely to die following surgery than those who had not experienced a weight loss of this magnitude. Among those age 60 and over, the death rate was 11 times higher for those who had lost 10 pounds or more than for those who had not (184).

Simple indicators like weight loss are useful for initial screening, but a thorough nutritional assessment is needed to select an appropriate formula or monitor response to treatment, For elderly people, research is needed to develop valid nutritional assessment procedures, including accurate nutritional standards for different age groups within the elderly population.

The Adequacy of Nutritional Formulas for Elderly People

Changes in body composition and metabolism associated with aging may necessitate adjustments in nutritional formulas for some or most elderly patients. Relevant age-related changes include decreased metabolic rate; decreased glucose tolerance; and changes in cardiac and kidney function that limit the patient's tolerance of the large volume of fluids required for TPN (51,55).

TPN formulas and modular enteral formulas are individually mixed and can be adjusted for elderly patients if the health care professionals treating these patients are aware of the necessary changes. To some nutritional support specialists, the necessary changes may be obvious. To health care professionals who are managing TPN and tube feeding for elderly patients but are not trained in clinical nutrition, however, the necessary changes may not be so clear.

Many, and perhaps most, elderly patients on tube feeding receive premixed formulas that are used exactly as they are received from the manufacturer. Lack of information about the dietary needs of elderly people—particularly very old people and those who are bedridden or otherwise extremely inactive—raises the possibility that some

elderly patients on tube feeding receive formulas that are inappropriate for their needs.

Another clinical issue is the adequacy of nutritional formulas for long-term use by patients of all ages. Insufficient or excessive amounts of specific nutrients may not affect patients on short-term treatment but can have a significant effect over time. Even if the correct amounts of certain nutrients are known and included in the solution, tube and intravenous feeding procedures can prevent their absorption and utilization. Infusion of nutrients directly into a person's veins, for example, results in immediate excretion of some nutrients that are normally stored in the liver. Nighttime infusion of nutritional formulas also affects absorption and utilization. As a result, some long-term nutritional support patients develop obscure deficiency syndromes (77,155). Clinical research on formulas for long-term use is needed.

The Effects of Withholding and Withdrawing Nutritional Support and Hydration

Clinical observation suggests that terminally ill people often reduce their intake of food and water as death approaches. For patients who are only hours or a few days away from death, dehydration can lessen nausea, vomiting, abdominal pain, and pulmonary secretions that cause gagging and choking and decrease the patient's level of consciousness and thus his or her perception of pain (29,180,234). For this specific group of patients, withdrawal of nutritional support may improve the quality of the individual's last hours or days. Some of these patients may suffer from thrist or dry mouth when treatment is withdrawn, but these symptoms can usually be alleviated with frequent mouth care, ice chips, small amounts of water, vaseline, and a room humidifier.

Little is known about the effects of withdrawing nutritional support and hydration and the course of dying without treatment for people who are terminally ill, comatose, or severely debilitated but for whom death is not imminent (122). Yet some discussions about withdrawing treatment from these patients are based on what is known about withdrawing treatment from patients for whom death is imminent. Caregivers point out, however, that some comatose, severely debilitated, and even terminally ill patients live a long time after nutritional support has been withdrawn and that malnutrition increases their susceptibility to infections and can cause deep decubitus ulcers that are painful for the patient and demoralizing for caregivers (130)163), Furthermore, although it is assumed that comatose patients do not experience hunger and thirst, it is not known to what extent severely debilitated and terminally ill patients for whom death is not imminent experience these feelings. More information is needed about the physiological effects of withholding and withdrawal for such patients.

A related clinical question pertains to the use of intravenous fluids when nutritional support has been withdrawn. Many caregivers are more reluctant to withdraw intravenous fluids than to withdraw tube feeding or TPN (133,155,192). On the other hand, continuing intravenous fluids after withdrawing feeding may prolong a patient's dying. Some terminally ill cancer patients are tube fed modified formulas that are not intended to meet their caloric or protein needs, but only to keep them hydrated and presumably more comfortable (155). Clinical research on the effects of these partial treatments is needed.

Ethicists and clinicians emphasize that a decision to withhold tube or intravenous nutrition and hydration should not mean abandonment of the patient and that palliative care should always be provided (35,121,228). Some of the nursing care measures described above, such as the use of ice chips to alleviate thirst, may lessen suffering for some dying patients. Other patients may be able to eat or drink small amounts of food or fluids that are insufficient to maintain life but nevertheless physically and emotionally satisfying. Tube and intravenous feeding are impersonal treatments, and in some cases, the decision to stop them and offer food and fluids by mouth instead may be comforting for the patient. For some families, the opportunity to bring in special foods or help with hand feeding is comforting (35,106,121,228). Clinical evaluation of these treatment approaches is needed.

The Relationship Between Dementia and Eating Disorders

An unknown number of patients on long-term nutritional support, especially tube feeding, have neurological diseases that cause dementia, but little is known about the relationship between these diseases and eating disorders. Parkinson's disease and stroke are known to cause physical difficulty with swallowing (46), and some patients with these diseases have dementia. Alzheimer's disease–the most frequent cause of dementia in elderly people—can also cause swallowing difficulty, at least in some patients (215). However, little is known about the prevalence of swallowing difficulties in persons with Alzheimer's disease or how often such conditions necessitate tube feeding. It is not known why some people with Alzheimer's disease or other dementing disorders stop eating while others do not, why some refuse hand feeding, and whether or how often these behaviors are related to swallowing disorders.

One study (190) found that 32 percent of the residents of one nursing home could not eat without physical assistance of some kind. The need for assistance was not correlated with a diagnosis of dementia or stroke, but it was highly correlated with swallowing disorders. The need for assistance was also correlated with low scores on a measure of cognitive ability—the Mini-Mental State Exam (MMSE) (78). None of the nursing home residents with an MMSE score indicating normal cognitive ability required assistance with eating, but 25 percent of those with scores indicating moderate cognitive impairment and 75 percent of those with scores indicating severe cognitive impairment required such assistance. Seven (9 percent) of the residents at this nursing home were tube fed. Of these seven, the researchers were able to examine four, all of whom had severe cognitive impairment (189).

Although cognitive impairment was correlated in this study with need for assistance in eating, cognitive impairment did not predict the need for assistance independent of swallowing difficulties. The researchers suggest that swallowing difficulties may be associated with only a specific type of dementia or only particularly severe dementia. In this context, it is important to note that 25 percent of residents with severe cognitive impairment were able to eat independently (190).

Another study (226) indicates that swallowing difficulties may not be common among Alzheimer's disease patients, even in the late stages of the disease. Some research suggests that eating disorders among these patients tend to develop when the patients have an infection, such as bronchial pneumonia, that decreases appetite (179,225).

Some people may believe that persons with dementia who do not eat should be tube fed regardless of the reason they do not eat; others may conclude that such persons should not be tube fed, again regardless of the reason they do not eat. A third group of people, however, may consider the reason for a dementia patient's eating problem a relevant factor in treatment decisions, and conclude, for example, that the decision to tube feed a dementia patient who has swallowing difficulty is less problematic than the decision to tube feed a dementia patient who does not eat for other reasons. In any case, good medical care requires greater understanding than now exists about the relationship between dementia and eating disorders.

Another problem in decisions about nutritional support for dementia patients is lack of information about the course of diseases that cause dementia (215) that makes it difficult to determine when such patients are terminally ill and how long they may live with and without treatment. Claire Conroy, a severely confused elderly woman who was the subject of intense legal debate about withdrawal of tube feeding, for example, died during early court proceedings even though it had not been expected that she would die imminently and tube feeding had not been withdrawn. If it had been clear that she was terminally ill and would die imminently with or without treatment, it is unlikely that her case would have been so controversial.

Federal Funding for Research on Nutritional Support for Elderly People

Federal funding for research on nutritional support is provided primarily by the National Institutes of Health, but none of the projects currently funded by the National Institutes of Health focus on use of these procedures for elderly people (193). The National Institute on Aging and the Department of Agriculture are funding research on nutrition and normal aging and the dietary requirements of healthy elderly people (81). The VA is funding several studies on nutritional support, most of which are not focused on elderly patients. However, the VA Geriatric Research, Education, and Clinical Center at Little Rock, Arkansas, conducts an ongoing research program on nutritional support for elderly patients. The VA Geriatric Research, Education, and Clinical Center at Bedford, Massachusetts, is conducting research on eating disorders in persons with dementia.

Some of the research that is needed to improve clinical decisionmaking and the quality of nutritional support procedures for elderly persons is basic biomedical research on human nutrition, nutrition and normal aging, and the relationship between nutrition and disease. Applied research to identify, develop, and evaluate products that meet the nutritional needs of elderly people is also needed. Some of the most important research questions, however-questions about the impact on patient comfort of withholding or withdrawing nutritional support and hydration from severely debilitated, comatose, and terminally ill persons who are not expected to die imminently; about the relationship between dementia and eating disorders; about reasons for patient refusal of tube or intravenous feeding; and about palliative care for persons who refuse the procedures or for whom they are futile-are primarily nursing issues. They may be best defined and addressed through the newly established National Center for Nursing Research at the National Institutes of Health. Other important questions, particularly questions about efficacy and patient comfort associated with different nutritional support procedures, are best addressed by nutritional support specialists, who are familiar with the range of treatment options and their pros and cons for different types of patients.

Professional Training and Expertise in Nutritional Support

Given the gaps in knowledge cited above, appropriate treatment decisions and ongoing care for elderly patients require the involvement of personnel who are trained to recognize malnutrition and eating disorders, to interpret assessment findings, to provide tube and intravenous nutrition and hydration, and to monitor patient response to treatment. Although some health care professionals who treat critically and terminally ill and severely debilitated elderly people have the requisite training in these areas, many do not.

In general, physicians and dietitians are responsible for nutritional assessment and treatment, although in many settings, nurses maybe the first to notice eating disorders and symptoms of malnutrition and are often the direct caregivers. Pharmacists are responsible for preparing TPN and, in some cases, enteral formulas (see ch. 10).

Physician training in basic human nutrition has been very limited (66,74,119,147,233). A recent survey by the National Research Council's Food and Nutrition Board found that only 27 percent of medical schools in the United States have required courses in nutrition. The National Research Council's report, ***Nutrition Education in U.S. Medical Schools,*** notes in particular the lack of medical training in enteral and parenteral nutrition and nutritional aspects of chronic disease, and it points out that medical board examinations now include no questions on enteral or parenteral nutrition or nutrition and the elderly (145).

All dietitians are trained in basic human nutrition and procedures for nutritional assessment. Dietitians also receive training in nutritional care of elderly people, but there is disagreement about the adequacy of this training. Most dietitians do not receive extensive training in assessment of critically ill patients. Dietetic training has changed with advances in nutritional support technology, so that dietitians trained recently are more familiar with current TPN and tube feeding techniques (49)194).

Pharmacists receive some training in nutrition throughout the pharmacy curriculum, although separate required courses on nutrition in the basic pharmacy program are unusual. The primary fo-

cus of their training in nutrition is the effects of malnutrition on drug therapy. Pharmacy students are usually introduced to parenteral and enteral nutrition in courses related to the selection and mixing of nutrient solutions (83,222).

Nurses receive training in basic nutrition and the importance of food and fluid intake in acute and chronic diseases. This training is often interspersed through the nursing curriculum, but a 1983 survey of nursing schools found that about half had separate required courses on nutrition (83). Yet many nurses have little training in nutritional support procedures, especially TPN.

Despite these generalizations about lack of training in clinical nutrition, some physicians, dietitians, pharmacists, and nurses have gained expertise in this field, partly through formal training but more often through experience in providing TPN and tube feeding, particularly in critical care settings. These nutritional support specialists work primarily in hospitals and are often members of nutritional support teams. Some have specific credentials in nutritional support, but many do not. There is currently no agreement about what credentials are needed and which organization or organizations should be responsible for certifying nutritional support specialists (195).[4] (See also ch. 10).

[4]**The American Society for Parenteral and Enteral Nutrition has published standards of practice for nutritional support nurses (10) and nutritional support dietitians (11), and standards** have been **drafted for pharmacists involved in the care of patients on nutritional support (13).**

Some patients in hospitals and at home receive care from hospital-based nutritional support teams. Such teams, that usually include a physician, a nurse, a dietitian, and a pharmacist, assist hospital staff with assessment and nutritional support of patients. In addition, some patients in hospitals, nursing homes, and at home, receive nutritional support services from individual professionals who have the necessary training and experience in clinical nutrition. However, as discussed in the following sections of this chapter, patients in some settings do not have the benefit of staff trained in nutritional assessment, tube feeding, or TPN. As a result, some elderly patients who might benefit from nutritional support may not be identified, and others may receive inappropriate treatment.

It has been noted that treatment options for elderly people are often limited by lack of knowledge about their special needs, a shortage of trained health care professionals to treat them, and other factors. As a result, the "best choice" for treatment is frequently not available (27). This observation accurately describes the current status of nutritional support and hydration for elderly patients in many treatment settings. Development of nutritional standards for elderly people, simple screening measures, and increased training for physicians, dietitians, pharmacists, and nurses in enteral and parenteral procedures and special considerations in their use with elderly patients could help to alleviate this problem.

UTILIZATION AND COST OF NUTRITIONAL SUPPORT AND HYDRATION

Industry data indicate that in 1984 about 1.4 million patients of all ages received nutritional support, 96 percent of them in hospitals (7) (see table 8-3). Although nutritional support techniques are basically the same in different settings, there are significant differences across settings in patient characteristics, health care personnel, cost of care, and reimbursement. Therefore, each setting is discussed separately.

Utilization and Cost of Nutritional Support and Hydration in Hospitals

Utilization of Nutritional Support in Hospitals

Industry sources estimate that more than 500,000 individuals of all ages received TPN in hospitals in 1984 and about 780,000 received tube feeding (7). Precise figures are not available because nei-

Table 8.3.–Persons Receiving Nutritional Support by Location and Type of Therapy, All Ages, 1984[a]

Location	Parenteral feeding	Enteral feeding	Total
Hospital	536,200 (96%)	780,300 (92%)	1,316,500 (94%)
Nursing home	15,600 (3%)	53,400 (6%)	69,000 (5%)
At home	4,600 (1%)	14,400 (2%)	19,000 (1%)
Total	556,400 (100%)	848,100 (100%)	1,404,500 (100%)

[a]These figures are from a marketing survey by Charles H. Kline Co, Fairfield, NJ. They provide valuable information about utilization but are considered high by some nutritional support specialists (68).

SOURCE: American Society of Parenteral and Enteral Nutrition, "1984 Nutritional Support Population Exceeds 6 Million," *Update* 8(4):8, 1985.

ther hospitals nor third-party payers regularly collect this information. Until late 1986, the widely used ICD-9 coding system had no procedure codes for tube feeding or TPN. Thus, there was a serious obstacle to collecting information on the utilization of these procedures. Newly assigned procedure codes for these procedures will facilitate data collection in the future.

Although no national figures are available on the number of elderly people who receive nutritional support in hospitals, reports from individual hospitals indicate that approximately 40 percent of the patients receiving TPN and 50 percent of those receiving tube feeding in hospitals are over age 65 (115). However, the percentages vary greatly in different hospitals.

Little is known about the characteristics of elderly patients on nutritional support in hospitals, but one 1984 study at the Albany Medical Center Hospital compared elderly patients who received nutritional support to those who did not. Of the 96 randomly selected subjects, 25 percent received tube feeding or TPN: 71 percent of these received only tube feeding; 12 percent received TPN, and 17 percent received both. There was a trend, although it was not significant, toward decreasing utilization with age—31 percent of patients aged 65 to 69 received nutritional support compared to only 21 percent of those over 70 (155).

About half of the elderly patients who received nutritional support in this study had diagnoses indicating central nervous system damage (notably stroke) compared to only 6 percent of those who did not receive nutritional support. About 20 percent of patients in each group had cancers of various types; in the group that received nutritional support, all the cancer patients had local or metastatic bowel involvement (155).

Comparison of the two groups of elderly patients on the basis of a functional assessment rating scale showed that the patients receiving nutritional support were more impaired in physical and mental health, activities of daily living, and ability to care for themselves independently. Their average length of hospital stay was significantly longer; a larger percentage died in the hospital; and a smaller percentage were discharged home compared to the patients who did not receive nutritional support (155). Although these findings cannot be generalized beyond the population surveyed, they do agree with findings of other studies showing that nutritional support patients of all ages are generally sicker and more functionally impaired than other patients with similar diagnoses (14).

Nutritional support, particularly TPN, is used for patients with each of the life-threatening conditions discussed in other chapters of this report–i.e., cardiac, respiratory and renal failure, and severe infections. Ventilator-dependent patients exemplify the complex relationship between nutritional support and other life-sustaining treatments. Patients who have an endotracheal tube (a tube placed through the mouth or nose into the trachea) for mechanical ventilation cannot take in food or fluids by mouth and, therefore, require tube feeding or TPN. Some patients on mechanical ventilation are also malnourished. Since malnutrition is associated with reduced ventilator drive and ventilator efficiency, nutritional support could be expected to improve outcome for these patients. Nutritional support may also be beneficial in weaning patients off mechanical ventilators (24,110). However, high glucose loads increase respiratory distress in some patients. Thus, the selection of an appropriate formula for a ventilator-dependent patient requires knowledge of the interaction of nutritional status, specific nutrients, and respiratory function. Moreover, frequent monitoring of the patient's response to nutritional support is essential to avoid complications and insure optimal outcome (20,73,86,143).

Malnutrition is common among hospital patients. The prevalence of malnutrition ranges from 17

to 60 percent among hospital patients of all ages (28,31,32,108,208) and is higher among elderly hospital patients than younger ones (28,91). Malnutrition is associated with increased morbidity, mortality, length of stay, and cost of care. One recent study of 800 hospitalized patients of all ages found that 55 percent were malnourished (4). Malnourished patients were three times more likely to die or suffer major complications than patients with normal nutritional status. Among patients who had pneumonia, hip fractures, or inflammatory bowel disease, those who were malnourished stayed an average of 2 days longer in the hospital, cost the hospital $1,160 more, and had charges of $2)480 more than those with normal nutritional status. Among patients undergoing hip, bowel, or abdominal vascular surgery, those who were malnourished spent 5 days more in the hospital, cost the hospital $2,750 more, and had charges of $5,575 more than those with normal nutritional status. Cost of care was higher, on average, for elderly patients but was much more closely correlated with the patients' nutritional status than their age (91).

Many malnourished patients can be treated with oral nutritional supplements and do not need tube feeding or TPN. Among the very large number of hospitalized elderly patients who are malnourished, however, some need tube feeding or TPN and do not receive it—sometimes because their poor nutritional status has not been identified or because its potential effect on clinical outcome is not recognized (137). No estimate of the number of these patients can be derived from available data, however.

Nutritional Support Personnel in Hospitals

Some hospitals have nutritional support teams to assist with or provide treatment, as discussed above. All VA medical centers that provide TPN are required to have a nutritional support team (114). But a 1984 survey of other hospitals found that only about 12 percent have a nutritional support team or a nutritional support service group (204).

Research indicates that clinical procedures necessary for safety and efficacy are frequently not followed and complications are more frequent when a nutritional support team is not involved in treating hospitalized patients on tube or intravenous feeding (67,69,146)161,1 74). Although no supporting data are available, it may also be true that in hospitals that do not have a nutritional support team or nutritional support service group, malnutrition is not recognized as frequently as in hospitals that do have such a team or group.

Cost and Reimbursement for Nutritional Support in Hospitals

Accurate data on costs, charges, and expenditures for nutritional support are difficult to obtain. Available figures vary greatly from one hospital to another, and figures reported as "costs" are often actually charges (21 1). According to one survey, the average cost of formulas, equipment, and associated staff time for TPN for hospitalized patients in 1985 was $196 per day (range: $25 to $500) (115). Other studies report average costs ranging from $75 to $400 a day for TPN formulas and associated staff time for hospitalized patients (14). If a patient remains in a hospital specifically to receive nutritional support, then the cost of hospitalization should be added to these costs to determine the overall cost of care.

Tube feeding is less expensive. One study showed that the average cost of formulas, equipment, and associated staff time for tube feeding for hospitalized patients in 1985 was $43 a day (range: $4 to $132) (115). Other studies report averages of $18 to $32 a day (14).

Medicare, Medicaid, Blue Cross, and other third-party payers reimburse hospitals for the care of elderly patients on nutritional support. Table 8-4 gives estimates of the percentage of patients receiving payment from each source.

Medicare is the primary payer for hospitalized elderly patients, and some nutritional support specialists and others believe that Medicare's prospective payment system (PPS) based on diagnosis-related groups (DRGs) discourages the use of nutritional support for the following reasons:

- The fixed Medicare payment rates for patients in each DRG are based on the average cost of treatment in the past. Some observers ar-

Table 8-4.-Source of Payment for Parenteral and Enteral Nutrition, All Ages, All Settings, United States, 1984'

Source of payment	Parenteral nutrition	Enteral nutrition
Medicare	33%	30%
Medicaid	8%	5%
Private insurance	58%	55%
Self pay	1%	10%

[a]Treatments provided in hospitals, nursing homes, hospices, and at home are included.
[b]These figures include payment for oral nutritional supplements in addition to tube and intravenous feeding.

SOURCE: "Nutrition Support," *Biomedical Business International* 8(3):23, 19S5.

gue that utilization of nutritional support has increased in many DRGs and that current DRG payment levels do not reflect this increased utilization (1)113,178).

- Patients with very different levels of severity of illness are grouped in the same DRG, and DRG payment levels appropriate for the average patient in each diagnostic category are significantly lower than the cost of treating the most severely ill patients in that category. Patients who receive nutritional support may be in any one of a large number of DRGs, but they tend to be among the most severely ill patients in each category. Some observers believe that low levels of reimbursement relative to costs for these "DRG losers" may discourage some hospitals from admitting them [14,102,173) and discourage other hospitals from providing expensive nutritional support (144). Although it can be argued in response that low reimbursement relative to cost for severely ill patients is balanced by relatively high reimbursement for less severely ill patients in the same DRG, that observation may not hold in the case of hospitals that provide nutritional support more frequently in each DRG than other hospitals; such hospitals may not be adequately reimbursed under the present Medicare payment system.
- Some DRGs cover patients with identical diagnoses except that one DRG includes patients who are over age 70 *or* have a comorbidity or complicating conditions while the companion DRG includes patients who are under age 70 and have no comorbidity or complication. Medicare payment is higher for the former DRG than for the latter. Malnutrition qualifies as a comorbidity or complication for some DRGs, and malnourished patients are included in the higher reimbursement category. However, in the case of patients who are over age 70—and are in the higher reimbursement category by virtue of their age–malnutrition does not increase the reimbursement the hospital receives for their care.
- Many patients who need nutritional support are classified as ***outliers*** under DRGs, usually because of length of stay significantly greater than average. Some people believe that the Medicare payment for outliers is insufficient to cover a hospital's costs in caring for these patients (14,102).

At congressional hearings prior to formation of the Prospective Payment Commission (ProPAC), the body established by Congress to recommend to the Department of Health and Human Services adjustments in PPS to accommodate new technologies and changes in utilization patterns, nutritional support was specifically cited as an example of medical treatments that would require study (8). In 1985, at the urging of the nutritional support industry and professional groups, ProPAC approved a study of Medicare payment for TPN (168). The study was canceled in 1986, however, primarily because lack of procedure codes for TPN made it impossible to collect the necessary data. It maybe reinstituted in the future if ProPAC continues to receive complaints about Medicare reimbursement for TPN (209).

One finding that would encourage the use of nutritional support, especially in the context of PPS, is proof that it saves hospital costs—i.e., that nutritional support decreases complications and length of stay, and, therefore, overall costs of hospital care (14,112,164)178,211). Proving this has been difficult, partly because of problems in defining severity of illness and identifying two groups of malnourished patients with comparable severity of illness, one of which was provided with nutritional support and the other not, A VA study (41) designed to overcome many of these problems is in progress, but the VA study addresses only surgical patients, and research on other patient groups is needed.

[1]*See* **ch. 2 for a discussion of comorbidity and complications.**

Medicaid coverage of nutritional support in hospitals varies by State, but in general, Medicaid pays for hospitalization and inpatient nutritional support for elderly people with low income and no Medicare coverage. In some States, however, the number of days of care that is covered and the level of reimbursement are very low. Blue Cross and other commercial insurers also pay for nutritional support in hospitals (8).

The VA provides treatment without charge for veterans in VA hospitals. OTA has not reviewed VA coverage or payment policies for nutritional support and hydration.

Medicare Part B (Supplementary Medical Insurance) reimburses physicians for hospital visits for nutritional support of their patients, and some analysts believe that higher payments to physicians for TPN than for tube feeding may encourage inappropriate use of TPN.

No national regulations limit the frequency of physician visits for nutritional support (84). However, Part B reimbursement is handled by 50 carriers across the country, each of which has considerable discretion in coverage policy (214). Some carriers, for example, the Illinois carrier, have issued guidelines for payment. For some time, the Illinois carrier limited coverage of physician visits related to TPN to once a day for the first 2 weeks, every other day for 2 weeks, and once a week thereafter; physician visits for tube feeding were limited to an initial visit and one followup visit (103). Medicare claims for visits in excess of these guidelines required special justification and were often denied,

Nurses, dietitians, and pharmacists who provide nutritional support services in hospitals are generally on salary, and their salaries were theoretically included in the cost figures used to establish Medicare's DRG payment levels. Unlike physicians, these providers do not receive any direct Medicare reimbursement. Nor is direct Medicare reimbursement provided for the services of a hospital's nutrition support team or a physician's services as administrator of such a team, In the context of cost-containment pressures created by PPS, a hospital must justify the salaries of these nutrition support professionals in terms of: 1) its commitment to high-quality care; 2) reduced malpractice liability; and/or 3) cost-effectiveness. It is not known whether the number of hospitals with nutritional support teams has increased or decreased in response to PPS.

Public Policy Issues for Nutritional Support in Hospitals

The primary public policy concerns emerging from the preceding discussion of the utilization of nutritional support in hospitals are the lack of skilled nutritional support professionals in some hospitals and the possible disincentives for the use of these procedures arising from PPS. These problems affect both access to treatment and quality of care for elderly patients in hospitals.

Utilization and Cost of Nutritional Support and Hydration in Nursing Homes

Utilization of Nutritional Support in Nursing Homes

Nutritional support and hydration are used more frequently in nursing homes than the other life-sustaining technologies discussed in this report, with the exception of antibiotics. Still, they are used for only a small percentage of all nursing home residents. Data from the 1985 National Nursing Home Survey show that about 26,000 nursing home residents (2 percent of all residents) were tube fed (220). Industry estimates for 1984 were slightly higher: Charles H. Kline Co. estimated that 53,400 nursing home residents (about 4 percent of all residents) received tube feeding and 15,600 residents (about 1 percent of all residents) received TPN (7).

Since about 85 percent of all nursing home residents are over 65 (218), it is apparent that most of those receiving nutritional support in nursing homes are elderly. Little else is known about their characteristics, diagnoses, functional or mental status, or average length of stay.

A 1984 survey of nursing homes' by the American Health Care Association found that an aver-

[5]In *1984,* the American Health Care Association, an organization representing *8,000* nursing homes and other long-term care facilities, surveyed its members about the use of nutritional support in their facilities. The response rate was low (5 percent), so results cannot be generalized, but the survey findings provide descriptive information about use of these treatments in some facilities.

age of four residents per facility were receiving tube feeding and about one resident for each six facilities was receiving TPN. More than half the facilities responding to the survey reported that they did not admit patients who require TPN. One-sixth reported that in the preceding 6 months, they had transferred or denied admission to patients who required tube feeding or TPN because the patients' needs exceeded the facility's ability to provide services. Some commented that they lacked adequate staff to provide nutritional support. Others cited payment problems (S).

State Medicaid regulations for licensing and certification of nursing homes affect utilization of nutritional support. In some States, Medicaid regulations mandate that certain nutritional support procedures cannot be used in nursing homes or in some types of nursing homes. In Washington, DC, intermediate care facilities (ICFs) can provide gastrostomy but not nasogastric or intravenous feeding (122).

Malnutrition among nursing home residents is common. One study (186) showed that many of the 115 residents of an Ohio nursing home (mean age 80) suffered from moderate to severe malnutrition by currently accepted nutritional standards e.g., 43 percent had abnormally low weight/height measures). A similar study in 2 Illinois nursing homes (162) found that 57 percent of the 227 residents (mean age 73) were malnourished.

Most malnourished nursing home residents do not need tube feeding or TPN. Increased staff attention to nutritional status, improvements in the quality and presentation of meals, hand feeding, and oral nutritional supplements could correct their nutritional deficits inmost cases. With such improvements, some nursing home residents who now receive tube feeding might be able to take in food and fluids by mouth. However, the number of such persons cannot be estimated because so little is known about why nursing home residents receive tube feeding or TPN.

Patients in a persistent noncognitive state—sometimes referred to as irreversible coma or persistent vegetative state—require tube feeding or TPN to survive. Despite the intense legal and ethical debate about the use of life-sustaining treatments for these patients, there is no reliable information about how many such patients there are in this country. Estimates of 5,000 to 10)000 are widely cited but cannot be confirmed. Data from the 1985 National Nursing Home Survey show that only about 1400 nursing home residents have a diagnosis of coma in their medical record (220), but individuals who are comatose are frequently given diagnoses that reflect the cause of the coma rather than a diagnosis of coma per se. No data are available on the number of persons in persistent noncognitive state (coma) in hospitals.

Nutritional Support Personnel in Nursing Homes

Lack of adequately trained staff to provide tube feeding and TPN is generally a more severe problem in nursing homes than in hospitals. Very few nursing homes employ nutritional support specialists. Thus, the responsibility for assessment, selecting formulas, and monitoring the resident's response to treatment lies with the physician, the facility dietitian, and nurses.

Physician visits are much less frequent to nursing home residents than to hospital patients (105), so physicians may be less involved in nutritional assessment and ongoing nutritional support for nursing home residents than for hospital patients. Dietitians are usually responsible for nutritional assessment in nursing homes, but Medicare and Medicaid regulations do not require a full-time dietitian, and many nursing homes get by with a dietary consultant who may be in the facility half time, 1 day a week, 1 day a month, or even less. The nursing home dietitian or dietary consultant may be responsible for nutritional assessment of 100 to 300 or more residents and also has other duties, such as recommending special diets, responding to resident complaints about the food, and in some facilities supervising the kitchen. If a dietitian is not available to assess each resident, that responsibility falls to nurses who are usually also responsible for day-today treatment (107,177).

Reliable information about how nutritional formulas are selected for nursing home residents is not available, but anecdotal evidence suggests that many nursing homes use premixed enteral formulas that are not adjusted to the needs of the individual. Concerns about the safety, quality, and

suitability of enteral formulas, discussed earlier, may be particularly relevant for nursing home use, because many nursing homes run within very tight financial constraints. Thus, they may purchase the lowest cost formula with little awareness of possible concerns about quality. Prevailing practices in nursing homes for monitoring residents' physical response to nutritional support are not known, but it is likely that there are also problems in this area.

In 1985, a Texas nursing home corporation was charged with murder for the death of a tube fed resident whose formula contained only 636 calories a day (154). It is unclear whether this case reflects knowing or unintentional neglect. However, some observers believe that slow, unintentional starvation of tube fed residents may not be unusual in nursing homes because of lack of staff trained to assess nutritional status, select an appropriate formula, and monitor the patient's response to treatment (103).

Although lack of adequately trained staff is an obstacle to safe and effective use of nutritional support in many nursing homes, three recent developments may lead to improvements. First, nutritional support specialists, who have demonstrated little interest in elderly nursing home residents in the past, are now focusing more attention on clinical issues related to their care. Second, the American Health Care Association is developing educational materials for its member facilities on ethical issues in nutritional support, clinical procedures, and alternate treatment methods (5). Finally, in response to Medicare's prospective payment system, some nursing homes are upgrading their staffs to provide more skilled care, and some hospitals are developing alternate level of care units for patients who are not acutely ill but need care that cannot be safely provided in nursing homes (337,83,169).

Cost and Reimbursement for Nutritional Support in Nursing Homes

OTA was unable to obtain estimates of the cost of tube feeding or TPN in nursing homes. It is likely that costs vary greatly in different facilities due to differences in personnel, nutritional support procedures, and patient characteristics. It is also likely that charges for nutritional support in nursing homes are related to Medicare and Medicaid payment policies, as discussed below.

Some people believe that an important aspect of the cost of nutritional support is the cost of long-term nursing home care for comatose and severely debilitated patients who would have died without tube or intravenous feeding and hydration. other people consider even the mention of such costs as objectionable.

No information is available about the cost of nursing home care for patients on nutritional support. The average cost of nursing home care varies greatly among States and in different facilities, but generally costs $20,000 to $30,000 or more per year (219).

Medicare covers nutritional support for nursing home residents under the Part B prosthetic device benefit that reimburses 80 percent of allowable charges. The resident, resident's family, Medicaid, or other third-party insurance is responsible for the remaining 20 percent.

Medicare Part B reimbursement for enteral nutrition in nursing homes is very controversial. Before 1980, nursing homes generally purchased enteral supplies in bulk and included the cost of the supplies in their daily charges for care. Beginning in 1980, medical supply firms developed a new marketing approach: enteral supplies were provided at no cost to the nursing home and billed to Medicare separately for each resident, usually at the same rate as supplies for patients on enteral nutrition at home. In 1984, the Inspector General recommended that Part B coverage of enteral supplies be eliminated for nursing home residents because charges for these supplies were excessi$_{ve}$(tw$_{o}$to three times open market prices). The Inspector General also recommended that nursing homes be allowed to include the cost of enteral supplies in their daily charges for patients whose nursing home care is covered by Medicare —a very small proportion of all residents. This approach was rejected because it would eliminate Medicare coverage of enteral supplies for the large proportion of residents whose nursing home care is not covered by Medicare (22 I). Instead, proposals by the Health Care Financing Administration (HCFA) would limit the amount of reimbursement for enteral supplies. The effect of this limitation

on access to nutritional support for nursing home residents is not known.

One point of disagreement between HCFA and medical supply firms is whether the firms that provide enteral supplies to nursing homes also provide other reimbursable services. The firms argue that they often provide training for nurses and other services for residents on tube feeding. HCFA claims that the firms seldom supply services for residents and that if training for nurses is needed, the nursing home should pay for it.

Medicaid policies that affect payment for nutritional support for nursing home residents vary considerably among States. Some States reimburse nursing homes at a flat rate for each Medicaid resident and make no additional payment for tube or intravenous feeding. Other States pay extra for residents who require tube or intravenous nutrition and hydration. This additional payment is included in the daily rate in some States, while in others Medicaid reimburses the nursing home separately for supplies and equipment used for each Medicaid patient, In many States, Medicaid reimbursement for tube or intravenous feeding requires prior authorization from the State Medicaid office (8). OTA has not analyzed the impact of differences among States in Medicaid coverage and reimbursement on the availability of these treatments.

The VA pays for long-term care of eligible veterans in community nursing homes and in VA hospitals, nursing homes, and domiciliary care facilities. No information was obtained by OTA about VA reimbursement for nutritional support and hydration for elderly VA patients in community nursing homes. Nutritional support for patients in VA facilities is provided without charge to the patient.

Medicare and Medicaid cover physician visits to nursing home residents, but the number of reimbursable physician visits is limited by both programs. As a result, frequent visits by a nutrition support physician, if one were available and willing to visit a nursing home resident, might not be reimbursed. Visits by dietitians or other nonphysician health care personnel are not reimbursed by Medicare or Medicaid, except insofar as they are included in the facility's daily charges.

Public Policy Issues for Nutritional Support in Nursing Homes

The most important public policy concerns emerging from the preceding discussion are the lack of information about the use of nutritional support procedures in nursing homes and questions about the quality of nutritional support procedures available to nursing home residents due to the lack of staff trained in nutritional assessment and nutritional support procedures. Particularly notable is the lack of involvement of skilled nutritional support specialists in the care of nursing home residents. Since Medicaid pays for almost half of the nursing home care in this country, improvements in quality of care for nursing home residents depend at least in part on Federal and State policies that determine level of reimbursement for Medicaid patients and required staffing in the facilities that care for them. Regulatory and reimbursement policies that encourage the involvement of nutritional support specialists in the treatment of nursing home residents could improve quality of care.

Utilization and Cost of Nutritional Support and Hydration in the Patient's Home

Utilization of Nutritional Support in the Home

Fewer patients of all ages receive tube feeding or TPN at home than in hospitals or nursing homes. Estimates range from 2,000 to 5,000 people of all ages on TPN and 15,000 to 20,000 on tube feeding (7,155).

The number of elderly patients on nutritional support at home is not known, but data from several sources' suggest that about 55 percent (range 17 to 59 percent) of people on tube feeding at home are over 65. This would be 8,000 to 11)000 elderly people. About 20 percent (range 15 to 29 percent) of people on TPN at home are over 65. This would be 300 to 1,500 elderly people (155).

[7]**These sources include three commercial home nutrition services representing about 5,400 patients and three relatively small registries representing about 1,400 patients. These sources overlap; that is, individual patients may be included in figures from two or more sources (155).**

Data from one registry show that the percentage of elderly patients among patients receiving TPN at home increased from 5 percent in 1978 to 17 percent in 1983 (153). There are no data on the percentage of elderly patients among patients on tube feeding at home in earlier years, but the percentage has probably been increasing (155).

Cancer is the most common diagnosis of patients of all ages on TPN at home, but the proportion of patients with cancer varies from 10 to 48 percent depending on the reporting source. Gastrointestinal diseases and disorders, e.g., Crohn's disease, ischemic bowel disease, and motility disorders, are also common diagnoses of home TPN patients.

Diagnoses of people of all ages on tube feeding at home include cancer, neurological disorders, such as stroke, and nonmalignant metabolic disorders. Little specific information is available about the diagnoses of elderly patients on nutritional support at home, but some data suggest that there are fewer cancer patients among elderly than younger patients (155).

The general health status, functional ability, and quality of life of people on home nutritional support varies greatly depending on the underlying condition that necessitates nutritional support. People with nonmalignant gastrointestinal disorders can often live quite normally once they learn the treatment procedures. Although many of them would die without nutritional support, their condition is seldom life-threatening so long as treatment continues. Since nutritional support usually does not cure their underlying disease, however, these people are often permanently technology- dependent.

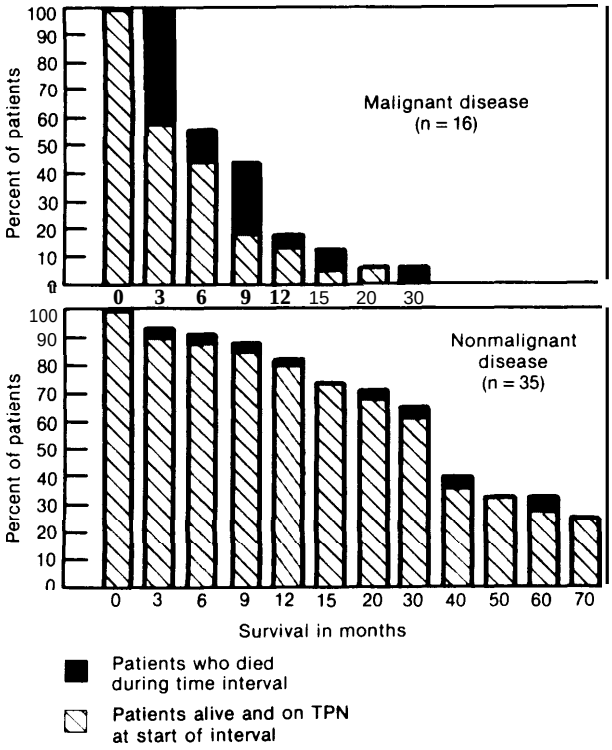
Nutritional support patients with cancer are often terminally ill and will die with or without tube feeding or TPN. In many cases, these procedures are used primarily to improve patient comfort, although in some cases, nutritional support can help to maintain their strength and may prolong their lives somewhat.

People with neurological disorders such as stroke may require nutritional support as a result of swallowing difficulty. For these patients, tube rather than intravenous techniques are usually used, and nutritional support can often prolong their lives significantly. Their functional ability and quality of life depend mainly on the extent of their neurological impairment. Cognitive and speech deficits and mobility limitations that are often associated with neurological impairment can reduce quality of life significantly. As noted throughout this report, however, judgments about quality of life vary widely depending on the values and perceptions of the observer. Thus, a level of impairment, functional ability, and quality of life that is acceptable to one patient and patient's family may be unacceptable to another patient and family.

Average duration of treatment for elderly people is not known, but data from one registry (153) indicate that over half the patients of all ages starting on TPN at home were still receiving treatment at the end of 1 year; about one quarter of the original patients were dead at the end of the year, and one quarter were alive but no longer on TPN. Survival time varies greatly depending on the patient underlying disease. As illustrated in figure 8-3, one study found that more than half of the cancer patients (average age 59 years) died within 6 months, and none survived beyond 30 months. In contrast, only about 15 percent of patients with nonmalignant gastrointestinal disorders (average age 56 years) died within 6 months; over half survived at least 3 years, and 15 percent were still alive after 8 years. No information is available about average survival time of patients on tube feeding at home (155).

Nutritional support procedures and equipment used at home are the same as or very similar to those used in hospitals and nursing homes, but home care patients and their families must play a much more active role in the treatment process. People on TPN at home and/or their families must learn to use the pump correctly; start and stop infusion; flush the catheter with saline solution and heparin following infusion; change the sterile dressing at the catheter insertion site; and recognize and respond to problems such as blockage of the catheter or air entering the bloodstream via the catheter (40). Some people on TPN at home mix their own formulas, and they must learn sterile technique and how to measure and combine the ingredients. Others use premixed formulas

Figure 8=3.—Survival of Albany Medical Center Patients on Home TPN With Malignant and Nonmalignant Disease



SOURCE: Oley Foundation, "Nutritional Support and Hydration for Critically and Terminally Ill Elderly, " prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC, 1985.

that are usually supplied by a hospital-based or commercial home nutrition service.

Tube feeding at home is less complex than TPN, and sterile technique is not necessary. However, patients and/or their families must learn to use the pump correctly, if a pump is needed; to check the placement of the tube; to monitor the flow rate and temperature of the formula; to flush the tube with water after infusion; and to be aware of potential complications such as aspiration of formula into the lungs. Some patients and/or families who mix enteral formulas themselves need to learn the process, but many patients, probably the majority, use premixed formulas (148).

Nutritional support specialists agree that it usually takes about 2 weeks in the hospital to train patients who are going home on TPN (85)89)101). Training for patients going home on tube feeding usually takes 3 to 6 hours over the course of several days in the hospital. Obviously, the patient's physical, emotional, and mental status affect training time.

There is concern that incentives for shorter hospital stays created by PPS and other cost containment programs restrict the time available for training patients who are going home on nutritional support and ultimately will reduce the safety and quality of home nutritional support for these patients (100). No data are available to determine whether training times have decreased in response to PPS and other programs, and, if so, whether this change has affected the safety and quality of care.

Nutritional Support Personnel for Home Care

From 1969, when the first patient went home on TPN, until 1979, when the first commercial home nutrition service entered the market (212), home nutritional support patients were managed by hospital-based nutritional support teams. Patients usually picked up their supplies from the hospital pharmacy and transported them home. Training was provided in the hospital, and followup visits from visiting nurses were discouraged, because the nurses were generally not trained in TPN or tube feeding and their involvement often caused more confusion than benefit (155).

As home nutritional support became more accepted, pharmaceutical, hospital, and medical supply companies established home nutrition services. These companies provide many services not available from the early no-frills, hospital-based programs, including delivery of supplies, training in the home, followup visits by trained staff, and assistance with third-party billing. Such companies have extended the use of home nutritional support by providing physicians who are not trained in clinical nutrition with access to specially trained nurses, dietitians, and pharmacists to monitor their home patients (155). Some nutritional support specialists and others have expressed concerns about the quality of care provided by some commercial home nutrition services. While recognizing that some of these companies provide excellent care, some analysts worry that physicians may not adequately supervise their home

patients who are managed by the companies, and that physicians who are not experienced in nutritional support may delegate too much responsibility for treatment decisions to non-physician staff of the company (61,85,188).

Commercial home nutrition services are not regulated by the Federal Government. It has been suggested that some of these companies do not provide adequate services for their home nutritional support patients and that regulation of the industry may be needed to ensure safety and quality of care.

Standards for home nutrition care have been published by the American Society for Parenteral and Enteral Nutrition, These standards delineate the role of the physician and other nutritional support service providers, the need for written policies and documentation of services, and procedures for patient selection, monitoring, and termination of home nutrition support (9). At present, however, there is no mechanism for enforcing these standards.

Photo credit: Foster *Medical Corp.*

Commercial home nutrition services provide training in the home for nutritional support patients and their families.

Cost and Reimbursement for Nutritional Support in the Home

No precise information is available about the cost of nutritional support at home. Both costs and charges vary considerably, depending on the specific procedures, supplies, formulas, and related services that are used and whether administrative and other costs are included. One OTA contractor estimates that charges for TPN at home typically range from $50,000 to $100,000 per year and that charges for enteral nutrition at home range from $3000 to $12,000 per year (155)$_0$

Medicare, Medicaid, and most private insurance cover tube feeding and TPN at home under specified circumstances. Nevertheless, arranging financing for home care patients is one of the most difficult aspects of nutritional support at home, and in some cases, decisions about whether to send patients home on nutritional support depend on the availability of reimbursement (101,171,182).

Medicare funding for tube feeding and TPN at home is provided, as it is in nursing homes, under the Part B prosthetic device benefit. Coverage of home nutritional support under the Part B prosthetic device benefit has three important implications:

1. Medicare reimbursement is provided for 80 percent of covered charges, and another source of payment must be found for the remaining 20 percent (the patient's required copayment);
2. the prosthetic device benefit requires that a patient have "a permanently ***inoperative*** internal body organ or function thereof" (217), and therefore does not extend to patients who require short-term treatment; and
3. under the prosthetic device benefit, accessories and supplies, such as catheters, pumps, dressings, and nutrient solutions are covered as parts of the device. Initial training for the patient or family is also covered, but since the prosthetic device is expected to replace an inoperative body organ, coverage for continuing services is theoretically unnecessary.

At present, there is disagreement between HCFA and home nutritional support providers about what continuing services are and should be pro-

vialed for patients on home nutritional support. Providers argue that services are essential for safe and effective treatment for many patients and that Medicare reimbursement under the prosthetic device benefit should include an allowance for continuing services. In contrast, HCFA argues that many commercial home nutrition services provide few services and that current reimbursement, which includes an allowance for initial training, is more than adequate.

Continuing services associated with home nutritional support could be provided under the Part A Medicare home health care benefit. This approach is not workable at present, however, because the home health care benefit covers only short-term or intermittent skilled nursing care. Furthermore, few home health care agencies employ nurses trained in nutritional support, and services provided in the home by dietitians are not covered by Medicare.

The number of patients receiving Medicare reimbursement for home nutritional support has grown rapidly in the past few years. In 1984, in order to contain escalating costs and eliminate what some considered abuses in the program, HCFA issued new guidelines for Medicare coverage of home nutrition. The new guidelines state that patients must require nutritional support for at least 90 days; that reimbursement is allowed only for the simplest (and thus least costly) pump that can be used; and that patients are expected to mix their own formulas unless a physician justifies in writing the need for premixed formulas (8). Each of these guidelines could limit access to appropriate care for some patients. However, OTA is not aware of instances in which elderly patients have been denied Medicare reimbursement on the basis of the guidelines.

HCFA has questioned the charges submitted by some home nutrition services and has proposed new fee screens. Industry representatives object to the way in which these fee screens were developed and to the proposed reimbursement levels (2). OTA has not analyzed the prevailing charges for home nutritional support or the adequacy of HCFA's proposed fee screens.

Medicaid and most private insurers pay for home nutritional support in specified circumstances. Medicaid policies vary among States, but many States require pre-authorization for treatment, and decisions about coverage are often made on a case-by-case basis. Some Medicaid programs follow Medicare guidelines for coverage. Blue Cross and Blue Shield and most other commercial carriers now cover home nutritional support, although policies vary with respect to coinsurance and deductibles.

Public Policy Issues for Nutritional Support at Home

The primary public policy issues arising from the preceding discussion of home nutritional support are potential limitations on access to home nutritional support due to Medicare coverage and reimbursement policies and questions about the quality of care provided by some commercial home nutrition services.

Because of the high cost of TPN and to a lesser extent, tube feeding, most individuals and families cannot afford nutritional support at home without third-party insurance coverage. Some analysts believe that current and proposed Medicare regulations limit access even for long-term treatment. Moreover, since Medicare does not cover temporary or short-term nutritional support at home, some patients who receive nutritional support in the hospital but are discharged before the course of treatment is completed–a situation that is likely to occur more frequently because of incentives for early hospital discharge related to Medicare's prospective payment system -cannot be reimbursed for continued treatment at home. Nor does Medicare cover short-term nutritional support at home for malnourished patients prior to hospitalization for surgery or other treatments.

A related issue is access to nutritional support for patients who are physically or mentally unable to care for themselves and have no family to assist them at home. Although it is sometimes possible to provide 24-hour assistance for such patients in the home (124), the cost of this care is prohibitive for most individuals, and public funding is seldom available for it, As a result, such patients may be placed in nursing homes. Anecdotal evidence suggests that in some cases-especially if the patient requires TPN and there is no nurs-

ing home in the area that will accept the patient on TPN—hospital staff may decide not to initiate treatment, and the patient may die.

Although some people advocate increased use of nutritional support procedures at home as a lower cost alternative to providing them in hospitals, others fear that some patients could be kept alive on expensive nutritional support at home with little real benefit to them. These issues are discussed below.

MAKING DECISIONS ABOUT NUTRITIONAL SUPPORT AND HYDRATION

Decisions about the use of nutritional support and hydration are based on clinical, legal, ethical, and financial considerations and reflect the training and preferences of the health care providers involved in the decision and in some cases the wishes of the patient and family. Clinical and financial considerations that affect decisionmaking have been discussed above. Decisionmaking practices vary by setting and are discussed later in this section.

Legal and ethical considerations affect decisions about the use of nutritional support and hydration in all settings. They are discussed at some length here because of their importance in the debate about public policy regarding nutritional support and in individual treatment decisions.

Legal and Ethical Considerations in Decisions About Nutritional Support and Hydration

Legal Cases Involving Nutritional Support and Hydration and Their Implications for Clinical Decisionmaking

Most court cases involving nutritional support and hydration have concerned withholding or withdrawing treatment, but a few cases have dealt with access to treatment and quality of care. The first legal case invoking withdrawal of nutritional support and hydration from an adult was decided in 1983. Since then, State courts have ruled on many such cases. Six of the most frequently cited cases are summarized in box 8-A.[a] Each of these cases resulted in a decision that authorized withholding or withdrawal of nutritional support and hydration in certain circumstances. The rulings remain controversial, however, and some legal scholars and others disagree with various aspects of each decision.

From the point of view of clinical decisionmaking, it should be noted that although as of early 1987, there was considerable agreement among court decisions with regard to nutritional support and hydration, this was not true at any time previously. In early 1986, for example, the Massachusetts court ruling that Paul Brophy's gastrostomy tube could not be withdrawn was still in effect, as were a Florida court ruling that Helen Corbett's nasogastric tube could not be removed, and a California court ruling that Elizabeth Bouvia could not refuse tube feeding (see ch. 3). Moreover, a few recent lower court cases have resulted in rulings that tube feeding could not be withdrawn; these decisions were on appeal as of early 1987 (200). Thus, although the most recent court decisions involving nutritional support and hydration have authorized withholding or withdrawal, it is understandable that physicians, nurses, hospital and nursing home administrators, and others remain unsure about the mandates of the law.

Given this uncertainty, health care professionals are likely to provide nutritional support and hydration in cases they are unsure about. This likelihood is enhanced by the inclination of health care professionals to '(err on the side of life" and by the fear health care professionals have about negative publicity for withholding or withdrawing nutrition and fluids.

The threat of a criminal murder charge is an even stronger disincentive to withholding ***or*** withdrawing nutritional support and hydration. No physician has ever been convicted of murder for withholding or withdrawing these procedures (see ch. 3). However, one district attorney has stated:

[a] ***See*** **also the Bouvia case** ***(36)*** **discussed in ch. 3.**

Box 9-A.—Court Cases Involving Withholding or Withdrawal of Nutritional Support and Hydration

Barber v. Superior Court **(California, 1983) (21).**—In 1982, Clarence Herbert, 55, had a heart attack during routine surgery. He became comatose, and was put on a mechanical ventilator and intravenous fluids. Three days later his doctors and his wife agreed that he should be taken off the ventilator and allowed to die. When the ventilation was removed, he began to breathe. Two days later his doctors and his wife agreed that he should be taken off intravenous fluids, and he died in a few days of pneumonia and dehydration.

A nurse contacted the local district attorney, and the doctors were charged with murder. The district attorney argued that nutritional support and hydration are not medical treatments but simply "conduits for food and water." One complaint of the prosecution was the rapidity of the decision to stop treatment.

Charges against the doctors were dismissed by the Court of Appeals that ruled that nutritional support and hydration are like other medical treatments and may be withheld or withdrawn under some circumstances. The court restated the general rule "that physicians have no duty to continue treatment that is 'futile' or 'has proved to be ineffective'" (16,87; see also ch. 3).

In re Hier **(Massachusetts, 1986) (83).**—Mary Hier was a 92-year-old nursing home resident who had been a patient in a psychiatric hospital for 57 years before being transferred to the nursing home in 1983. She had been fed through a gastrostomy tube since 1974.

In 1984, she was hospitalized because she had pulled out her gastrostomy tube several times, and nursing home staff could not replace it. The nursing home petitioned the court to appoint a guardian with authority to consent to replacing the tube. The lower court refused, and the Appeals Court affirmed that ruling, finding that Mrs. Hier was incompetent to make the decision but that the treatment was not required because it was intrusive and burdensome; because Mrs. Hier had made her opposition to it clear by repeatedly removing other tubes; and because restraints might be required to keep her from pulling the tube out.

After the Appeals Court ruling, the guardian ad litem went back to the lower court. The original judge heard additional witnesses and ordered the tube replaced. It was, and Mrs. Hier lived. However, this lower court decision does not affect the judicial precedent created by the Appeals Court decision (17).

In re Application of Plaza Health and Rehabilitation Center **(New York, 1984) (58).**—Ross Henninger, an 85-year-old, mentally competent, nursing home resident, decided to starve himself to death. A New York Supreme Court judge ruled that Mr. Henninger had the right to do so and that the nursing home had neither the right nor the obligation to force feed him (see also ch. 3).

In re Conroy **(New Jersey, 1985) (24).**—Claire Conroy, an 83-year-old, mentally incompetent, nursing home resident, was hospitalized with gangrene of her left leg. Her nephew, who was her legal guardian, refused consent for amputation of the leg and petitioned the court for authority to have her nasogastric tube removed. The petition was granted but immediately appealed, and a stay was granted. Mrs. Conroy died with the nasogastric tube in place. After her death, the Appeals Court ruled that removal of the nasogastric tube would have been homicide, and that "Mrs. Conroy would not have died as a result of an existing medical condition, but rather she would have died, and painfully so, as the result of a new and independent condition: dehydration and starvation" (87). In 1985, the New Jersey Supreme Court reversed this decision, ruling that the feeding tube could have been withdrawn (see also ch. 3).

Brophy v. New England Sinai Hospital **(Massachusetts, 1986) (38).**—Paul Brophy, a 48-year-old man, suffered a brain hemorrhage in 1983 and never regained consciousness. In 1985, his family requested that his gastrostomy tube be removed since he had previously stated on several occasions that he did not want to be kept alive artificially. The Massachusetts Probate Court ruled that the gastrostomy tube could not be removed.

In 1986, the Massachusetts Supreme Judicial Court set aside the lower court ruling that prevented removal of the feeding tube but upheld the lower court ruling that hospitals cannot be compelled to withhold feeding when it violates their ethical principles (38).

***Corbett* v. *D'Alessandro* (Florida, 1986) (62).—Helen Corbett was an elderly woman who had been in a coma since 1982 and was fed through a nasogastric tube. In 1984, her husband petitioned the court to allow removal of the tube. Mrs. Corbett died with the tube in place after the court hearing but prior to the decision. The court ruled that discontinuing nasogastric tube feeding is barred by the Florida living will statute.**

In 1986, the Florida Appeals Court overturned this ruling and found that there is a Constitutional right to privacy that protects an individual's right to refuse nutritional support even when the State living will statute does not allow refusal of nutritional support. The Florida Supreme Court denied a request to review this decision (199).

SOURCE: Office of Technology Assessment, 1987.

> (T)he most fundamental function of the criminal justice system is to protect society from people who would deliberately deprive other people of their lives. Depriving a patient of food and fluid may well make sense in a variety of medical cases. However, when that determination leads inevitably to death, as is the case with deprivation of nutrition and hydration, then the medical profession has crossed over into an area beyond medicine, (and) . . . that practitioner ***rightfully*** runs the risk of scrutiny and penalty by the criminal justice system *(191).*

Even if legal charges do not lead to conviction, many physicians fear the impact of such charges on their other patients, their reputations, and their malpractice insurance rates.

In the Conroy decision, the New Jersey Supreme Court set out procedures for decisions about withholding or withdrawing nutritional support from an incompetent nursing home resident. The court ruled that a guardian must be appointed; the State ombudsman for Institutionalized People must be notified and must immediately investigate the case for possible patient abuse; and 3 physicians must agree that the patient has no more than 1 year to live (18,65) (see ch. 3).

Some analysts argue that requiring time-consuming and cumbersome procedures, such as the appointment of a guardian and the involvement of three physicians, discourages decisions to withhold or withdraw nutritional support. They also argue that requiring an investigation by the ombudsman (whose function is to investigate abuse cases) equates withdrawal of nutritional support with patient abuse. This is a clear disincentive for such decisions (18,121)—a disincentive that is applauded by some and regreted by others.

In the first year of the new procedures, only one case was submitted to the ombudsman (see below). Some people believe that families and health care professionals in New Jersey may be making decisions about withholding and withdrawal without following the required procedures, because they are too cumbersome (206).

In June 1987, the New Jersey Supreme Court handed down rulings on two cases that appear to substantially modify the requirements created by the ***Conroy*** decision. One case concerned Hilda Peter, a 65-year-old nursing home resident who was in a persistent vegetative state and was tube fed. In 1986, the Ombudsman refused to allow removal of her feeding tube because there was no certainty that she had less than 1 year to live (198). In its June 1987 decision, the court determined that since Miss Peter was in a persistent vegetative state, like Karen Quinlan, the life expectancy test required by the Conroy decision should not have been applied and that the tube could be withdrawn on the basis of evidence that she had previously expressed a desire not to be maintained in such a condition.

The other case concerned Nancy Jobes, a 31-yeard-old nursing home resident who was in an irreversible coma and had been tube fed for 6 years. In 1986, a New Jersey court approved her husband's request to remove the feeding tube, but the decision was appealed (96). In its June 1987 decision, the court determined that the family could exercise the patient's right to refuse tube feeding without involvement of the Ombudsman.

A final legal question that may affect decisions about withholding or withdrawing nutritional support and hydration is the liability of nurses for these decisions. While physician liability has received considerable legal attention, the liability of nurses has received less attention. Yet nurses are usually responsible for providing the procedures, and they may have access to more information than the physician about patient and family wishes and the patient's physical and emotional response to providing, withholding, or withdrawing nutritional support **(229).**

In addition to cases involving withholding or withdrawal, several legal cases have dealt with access to nutritional support and quality of care. While cases on withholding and withdrawal have generally involved tube feeding and nursing home residents, these cases involve TPN and hospital patients. For example, in 1985, a Cook County, Illinois jury awarded $2.3 million in a malpractice case involving a 53-year-old patient who died in 1980. He was receiving TPN in a hospital, and the suit alleged that the physician and the hospital failed to monitor his blood sugar level adequately. He went into a coma when his blood sugar rose to dangerously high levels, and he died 4 months later without ever regaining consciousness (138).

In 1982, a family was awarded $400)000 following the death of a patient with a gastrointestinal disease. The family alleged that the patient's death was caused partly by the physician's failure to provide nutritional support. Some observers expect an increase in such suits (201)208).

The decisions in these cases suggest that nutritional support has become standard care for certain conditions and that procedures such as careful monitoring of blood sugar levels are considered routine when nutritional support is used. On the one hand, these decisions create an incentive for increased use of nutritional support. They could also encourage the formation of nutritional support teams, since patients treated by these teams experience fewer complications than other nutritional support patients (201). On the other hand, PPS is believed by many analysts to discourage the use of nutritional support, as discussed earlier. These contradictory pressures place physicians and hospital administrators in a difficult position in which nutritional support treatments are simultaneously required to provide standard care and avoid malpractice liability, yet may not be adequately reimbursed in some cases.

Legal and Ethical Issues Surrounding the Use of Nutritional Support and Hydration

In connection with nutritional support and hydration, the legal and ethical issues about which there has been the most debate are:

- whether tube and intravenous nutrition and hydration are medical treatments or basic supportive or nursing care,
- whether they are extraordinary or ordinary care,
- whether they are burdensome for the patient,
- whether withdrawing tube or intravenous nutrition and hydration from terminally ill or severely debilitated patients is killing or allowing the patient to die,
- whether '(quality of life" should be a factor in decisions about the use of nutritional support and hydration, and
- whether nutritional support and hydration may be withheld or withdrawn from pati[e]nts who are not terminally ill and not expected to die imminently.

Differences of opinion among people about these issues may reflect: 1) differences in religious and cultural background that affect beliefs about death and the obligation of the individual and society to care for sick and dying people; 2) differences in previous experience with nutritional support and hydration that affect beliefs about the efficacy and risks of the procedures; and 3) other personal emotional and psychological factors that affect the individual's attitudes about starvation, suffering, the value of life, and its relationship to quality of life.

For health care professionals, training, experience, and professional ethics also play a role in determining attitudes. For example, many ethicists have concluded that the distinctions that are sometimes drawn between extraordinary and ordinary care are neither valid nor helpful in decisions about life-sustaining treatment (see ch. 4). Yet some health care providers consider these distinctions important and are reluctant to withhold

treatment that their training and experience indicates is ordinary. Nutritional support and hydration are the prime examples.

The symbolism of nutritional support and hydration also affects attitudes, as discussed earlier. Conflicting symbols are particularly difficult. On the one hand, the symbolic relationship between feeding and caring and the image of starving the patient to death encourage a decision to treat. On the other hand, the image of force feeding that may arise, for example, when frail elderly patients must be physically restrained for insertion of a nasogastric tube and to keep them from pulling it out, argues for withholding nutritional support and hydration.

Conflicting attitudes and symbols mean that these decisions are particularly difficult in multiperson settings, like hospitals and nursing homes, and may result in disagreements between staff members. Such a disagreement led to the *Barber v. Superior Court* case (117). A similar situation arose at a Seattle nursing home:

> **In 1984, several nurses at the Crista Nursing Center refused to withdraw a feeding tube from a 74-year-old stroke patient who was diagnosed as terminally ill and whose physician and family agreed that tube feeding should be discontinued. The family got a court order to have the patient transferred to another facility and to withdraw tube feeding, and the patient died in the other facility. Crista Nursing Center asked for the resignation of one or more of the nurses, but later withdrew the request.**
>
> **In 1985, at the same facility, several nurses refused to withdraw a feeding tube from an 82-year-old patient, although the patient's physician and family agreed that nutritional support should be discontinued. The nurses were told they would be moved to another nursing unit. The tube was removed, and the patient died. One of the nurses sued the nursing home, the administrator, and the director of nursing, alleging that removing the feeding tube is "illegal, immoral, [and] contrary to (her) religious beliefs" (165).**

Conflicting attitudes about withholding and withdrawing nutritional support and hydration make it likely that any federally mandated guidelines about which patients should or should not receive these procedures would result in decisions that run counter to the strongly held beliefs of many people.

Some ethicists fear that allowing withholding and withdrawal in some cases will create a "slippery slope," eventually leading to withdrawal of nutritional support and hydration from handicapped and "pleasantly senile" people (42,87,157, 192). Others argue that decisionmaking based on the "slippery slope" concept sacrifices the welfare of individual patients in order to protect society, which may itself be unethical (52,121).

Legal and ethical debate about nutritional support and hydration has focused on whether they are correctly considered medical treatments or basic supportive or nursing care. This distinction is important for legal purposes because courts have ruled that competent persons have a right to refuse medical treatments and that medical treatments can legally be withheld or withdrawn from incompetent patients, both within certain limits. Many ethicists agree that the distinction between medical treatment and basic supportive or nursing care is valid for ethical analysis. However, some people, including some caregivers in hospitals and nursing homes, who are unfamiliar with the legal and ethical arguments, believe that withholding and withdrawing nutritional support and hydration is wrong, regardless of whether the procedures are defined as medical treatments or basic supportive or nursing care.

One question that is rarely discussed in this context is whether patients have a right to refuse basic supportive or nursing care. Yet many health care providers recognize such a right. It is unclear how recognition of a patient's right to refuse such care relates to the ongoing legal and ethical debate about whether nutritional support and hydration are medical treatments or nursing care and how recognition of a right to refuse nursing care is related to caregivers' attitudes about withholding and withdrawing nutritional support and hydration (232).

The recent decision of the Massachusetts Supreme Judicial Court in the ***Brophy*** **case (38)** allowed removal of Mr. Brophy's gastrostomy tube but does not compel the hospital or individual health care professionals to withhold feeding if that would violate their ethical principles. Instead,

the court authorized Mr. Brophy's transfer to another setting for withdrawal of the tube. This "conscience clause" in the Brophy's decision may alleviate concerns of health care professionals and facilities about being forced to withdraw these procedures against their convictions. In some cases, however, conflict is inevitable between this right of health care professionals and facilities, on the one hand, and the right of the patient to refuse treatment, on the other hand.

The conflict arose in the recently decided case of Beverly Requena, a 55-year-old woman with amyotrophic lateral sclerosis (Lou Gehrig's disease), a disease that involves degeneration of portions of the spinal cord, progressive loss of muscle control, increasing paralysis, and eventual death. In June 1986, Mrs. Requena notified the hospital where she was a patient that when her disease progressed to the point where she could not swallow, she would refuse tube feeding. The hospital has a policy against withholding food or fluids from any patient and therefore asked Mrs. Requena to leave. She refused, and the hospital went to court to force her to do so.

In 1986, the Superior Court of New Jersey ruled on the case. The judge stated:

> There is no good outcome to this case. Regardless of any decision made by me or anybody else, one way or another, in one place or another, Beverly Requena will die an unpleasant death in the relatively near future. Going to (another hospital) is a realistic alternative. But if Mrs. Requena goes there, she will experience extra suffering over and above the grim suffering necessarily inherent in her disease and in her choice of no artificial feeding. Requiring (this) hospital to continue to care for Mrs. Requena even though she does not accept artificial feeding is also a real alternative. However, that would entail significant judicial interference with the policies of the hospital and would impose special burdens upon individual health care employees of the hospital (97).

The court ruled, finally, that Mrs. Requena had the right to refuse tube feeding and that she could remain in the hospital until her death. Without any doubt, however, this issue will arise again in other cases.

Although most of the issues discussed above have been the subject of lengthy legal and ethical debate, several other issues with profound legal and ethical implications have received little attention. They are:

- whether tube and intravenous nutrition and hydration must be provided for all patients who would benefit, and, if so, whether the government is obligated to pay for these procedures for people who cannot otherwise afford them;
- whether nutritional support, especially expensive TPN, must be provided for all patients who request it or whose families request it for them, independent of any demonstrable medical benefit to them; and
- whether tube and intravenous nutrition and hydration should be provided in facilities where there is no staff trained to evaluate the patient's need for treatment and provide it safely.

In general, these issues involve questions of access to care and quality of care, as opposed to questions about withholding or withdrawing care.

State Living Will Laws

Living will statutes in 20 States distinguish between nutritional support and hydration and other life-sustaining medical procedures. As of October 1986, statutes in eight States (Colorado, Connecticut, Georgia, Idaho, Maine, Missouri, Oklahoma, and Wisconsin) specify that nutritional support and hydration are ***not*** among the life-sustaining treatments people may refuse with a living will. In 12 States (Arizona, Florida, Hawaii, Illinois, Indiana, Iowa, Maryland, New Hampshire, South Carolina, Tennessee, Utah, and Wyoming), the language of the statutes is less clear but seems to say that nutritional support and hydration needed ***for patient comfort*** may not be withheld or withdrawn, implying that procedures that are not needed for patient comfort may be withheld or withdrawn. Living will statutes in other States either allow withholding and withdrawing of nutritional support and hydration or do not refer to them specifically (197).

In States where living will statutes do not allow withholding or withdrawal of nutritional support and hydration, patients may retain basic common law and constitutional rights to refuse such pro-

cedures. The 1986 decision of the Florida Appeals Court in the Corbett case (62) supports this conclusion.

Conversely, anecdotal evidence suggests that even in States where living will statutes do allow withholding and withdrawal of nutritional support, a patient's refusal of tube feeding may not be honored, as illustrated in the following case:

> An elderly California man had a living will and a durable power of attorney drawn up by his lawyer prior to radical neck surgery for cancer. He told his doctors that he did not want nasogastric tube feeding, and they agreed to comply with his wishes. Nevertheless, following surgery, a nasogastic tube was inserted. Despite the efforts of his wife who had authority to make decisions for him through the durable power of attorney, the doctors refused to remove the tube, saying that it was medically necessary. When told about the living will and durable power of attorney a hospital social worker said, "Oh, that would never holdup in court." The tube remained in place until the man died 3 weeks later (59).

Making Decisions About Nutritional Support and Hydration in Hospitals

Decisions about nutritional support and hydration in hospitals are usually made by a physician, based on his or her perception of the patient's condition and the appropriate treatment for that condition; the physician's decision may also be affected by the opinions of other staff, the patient, and family, and legal, ethical, and financial considerations. Since no information was available at the start of this OTA assessment about how these decisions are made for elderly patients, a survey of nutritional support specialists was conducted for OTA.[9] Findings from the survey cannot be generalized beyond the individual respondents and the hospitals they represent, partly because of the low response rate (about 12 percent) and partly because of bias introduced by the fact that only hospitals that employ nutritional support specialists were included in the survey. Nevertheless, the findings, summarized below, provide some information about decisionmaking in these hospitals and the attitudes of some nutritional support specialists who treat elderly patients. OTA has no information about decisionmaking in other hospitals or about the attitudes of nutritional support specialists who did not respond to the surveyor of other health care professionals who are not nutritional support specialists but are involved in decisions about treatment for elderly patients in hospitals.

Survey respondents said that in the hospitals where they work, a team including a physician, a dietitian, and a nurse usually evaluates the patient. Once a decision is made to provide nutritional support, the dietitian usually selects the formula for tube feeding, while the physician and the pharmacist usually select TPN formulas.

Survey respondents indicated that the patient's age per se is not and should not be a consideration in decisions about whether to provide nutritional support. However, almost half said that the patient's mental status is a consideration in these decisions. The reason most frequently cited for this was the likelihood that confused patients will pull out the tube or catheter.

About three-quarters of respondents said that terminal illness is not a contraindication for nutritional support and that nutritional support can contribute to quality of life for terminally ill patients. However, about half said, "Terminally ill patients should not have their lives prolonged by nutritional support," and agreed that nutritional support "should be terminated when other life-support methods, such as respirators, are removed"; 31 percent disagreed with the latter statement, and 24 percent of respondents were unsure.

Most respondents disagreed with the statement, "Starvation is an acceptable way of dying for the terminally ill patient ." One individual commented, "Dehydration / starvation is a ***terrible*** way to die! Many times enteral tubes enable medications to be given which contribute to less painful deaths; also other medications which reverse illness. "

[9] During 1985, questionnaires were mailed to about 4,000 members of the American Society for Parenteral and Enteral Nutrition, a professional society that represents physicians, nurses, dietitians, and pharmacists involved in nutritional support. About 470 questionnaires were returned, some of which represent responses of more than one individual, since members at the same hospital submitted joint questionnaires in some cases (115).

About half the respondents said that complications are more common in elderly than younger people; 44 percent said that the rate of complications is about the same, and 2 percent said complications are less common in the elderly. Almost all respondents (93 percent) noted that patients with multiple diseases have more complications than those with a single disease, but the existence of multiple diseases was not seen as a contraindication for treatment. Thus, most of the respondents (91 percent) disagreed with the statement, "Nutritional support is dangerous to use in frail elderly patients."

The last item on the survey questionnaire was an open-ended question inviting comments on nutritional support of elderly patients. Representative comments from nutritional support specialists are cited below:

> "Many elderly people are strong enough to overcome the crisis of illness and go on to resume their lives. It seems discriminatory to withhold nutritional support only because of age."

> "When I first came to this facility, I was amazed at the physical appearance of the geropsychiatric patients. Visible signs of long-term . . . malnutrition were evident. After much persistence and determination (i.e., educating physicians and overcoming resistance from other direct care staff), patients with aggressive nutritional support were showing improved wound healing, increased resistance to infection and increases in visceral protein status."

> "Too often they are left without nutrition support of any kind while being bombarded with other forms of treatment. "

> "Nutritional support in the elderly is most frequently overlooked in many instances due to: (1) ignorance of special nutrient needs of elderly patients; (z) lack of knowledgeable personnel to consult, evaluate, monitor, and operate necessary equipment; **(3) cost** of products/equipment; (4) low priority of nutritional problems as compared to physical disabilities, failure to recognize potential relationships."

> "I care for some young patients (less than 65) and reluctantly support them (because they are in a vegetative state). Yet I have treated elderly patients (greater than 75) who are alert, ambulatory, and enjoy life even in the face of terminal illness."

> "I have seen patients that want to die but after nutritional intervention are glad to be alive."

Little is known about the attitudes of patients or family members toward tube or intravenous feeding or the role they usually play in the decisionmaking process. In general, hospitalized patients and their families tend to accept the advice of the physician about necessary medical procedures, and it is likely that most elderly patients and their families accept the physician's recommendation for tube or intravenous nutrition and hydration. However, some hospital patients refuse nutritional support if they are given the opportunity (19).

It is not likely that hospital patients or their families would request or demand nutritional support when it is not proposed by the physician. In the case of patients who cannot eat at all, the outcome—malnutrition and eventual death—is obvious, but for patients who are able to take in at least some food and fluids by mouth, the outcome is less obvious, and many patients and families may not be sufficiently aware of the relationship between nutritional status and outcome to request nutritional support. Nor are they aware of the potential risks involved in nutritional support or the need for careful monitoring once the procedures are initiated.

In many hospitals, formal consent from the patient or family is required for TPN and placement of enteral feeding tubes that involves surgery, e.g., gastrostomy or jejunostomy tubes, but is not usually required for nasogastric tubes (115,155). In some hospitals, nasogastric tubes are placed while the patient is unconscious during surgery, sometimes without the prior knowledge of the patient or family. In other hospitals, these procedures are routinely discussed with the patient or family ahead of time.

Making Decisions About Nutritional Support and Hydration in Nursing Homes

Decisions about the use of nutritional support for nursing home residents are often made in hospitals, and some patients on long-term tube feeding remain in the hospital for prolonged periods.

Since many of the same considerations that affect decisions about nutritional support for nursing home residents also affect these decisions for long-term hospital patients, much of the following discussion is also relevant to them.

Decisions about nutritional support for nursing home residents are ultimately made by the physician who writes the treatment orders. When such a decision is made in a hospital, the physicians may make the decision independently or consult with the patient family, staff nurses, the hospital dietitian, the social worker, and sometimes the patient. Nutritional support is frequently used on a short-term basis in hospitals, and anecdotal evidence suggests that when a decision is made in the hospital to initiate nutritional support for a long-term care patient, the decision is sometimes made without explicit recognition or discussion of its implications—that a patient may continue on nutritional support for the rest of his or her life, because once the procedures are started, many health care providers are reluctant to withdraw them (63).

When a decision to initiate nutritional support is made while a patient is in a nursing home, the physician is still responsible, but the dietitian and nurses frequently alert the physician to the need for treatment. Anecdotal evidence indicates that nutritional support is sometimes initiated for severely debilitated nursing home residents even when the physician would prefer to withhold it. This situation may occur because one or more staff nurses call the physician repeatedly to report poor intake of food and fluids, and eventually the physician orders tube feeding. In these instances, the nurses may be motivated by: 1) professional standards that require them to report significant changes in the resident's condition; 2) fear that they will be liable for the resident's death if they do not call the doctor; 3) a conviction that it is wrong to let such residents die of malnutrition or dehydration; or 4) their discomfort with watching the resident's condition worsen daily. In fact, some nurses resent a doctor's order to withhold or withdraw nutritional support when the doctor will not be present through the dying process.

Little is known about how or how often decisions are made to withhold or withdraw nutritional support from nursing home residents. In some cases, physicians may make these decisions independently, while in other cases, many individuals are involved, including the patient, the family, one or more physicians, nurses, dietitians, social workers, clergymen, lawyers, hospital or nursing home administrators, and even institutional review boards or ethics committees. Decisionmaking for most nursing home residents probably falls between these two extremes, but the difficulty of the decision and disagreement among those involved sometimes result in these cases being taken to court.

One of the most controversial questions in decisions to withhold or withdraw nutritional support is whether a patient's mental status is or should be a factor in the decision. In one study that addressed this question, physicians at a VA medical facility were asked whether they would tube feed a severely confused 70-year-old woman who was refusing to eat by clamping her mouth shut and spitting out food. Fifty-nine percent of the physicians said they would tube feed this patient, and 41 percent said they would not. In response to a general question, "How often do you attempt to tube feed ward patients with chronic irreversible dementia?" 4 percent of the physician's said "rarely"; 11 percent said "sometimes";

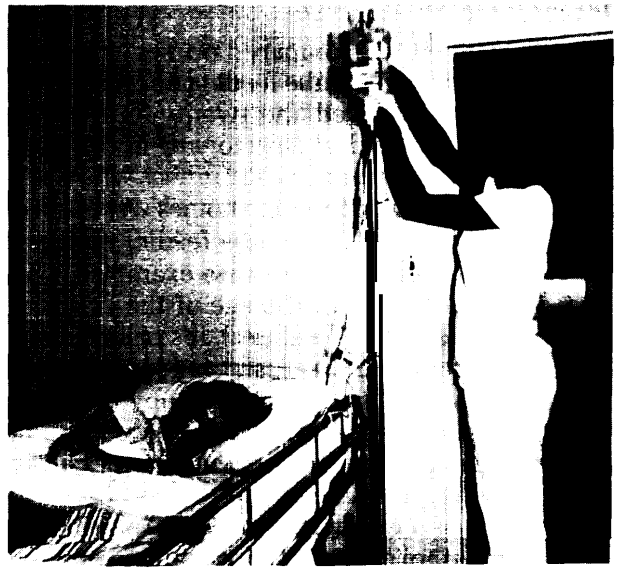


Photo credit: Gretchen Kolsrud

Severely debilitated nursing home residents are sometimes maintained for prolonged periods on nasogastric tube feeding.

41 percent said "most times," and 44 percent said "always" (109).

Nurses' attitudes toward this question were addressed in another study (155) in which the head nurse on each unit in one nursing home was asked which treatments were "too aggressive" for specific residents on her unit. According to the nurses, nasogastric tube feeding was "too aggressive" for 31 percent of the residents. This increased to 46 percent if the same residents became permanently unconscious. Nasogastric hydration was considered too aggressive for 11 percent of residents, increasing to 22 percent if they became permanently comatose. (Although these numbers may seem high to some readers, it is important to note that the procedures were considered appropriate for most residents; for example, nasogastric hydration was considered appropriate for 89 percent of the residents.)

All the nursing home residents from whom the nurses in this study said they would withhold nasogastric hydration had permanent neurological conditions resulting in impaired mental status. These patients comprised only 20 percent of all residents with impaired mental status in the facility, however, and the nurses said that the other 80 percent should receive nasogastric hydration. Thus, the patient's mental status alone was not the deciding factor (155).

A third study (229) compared nurses' and physicians' attitudes about tube feeding nursing home residents. One hundred and twenty-four physicians who were medical directors or house physicians in nursing homes and 157 nurses who were directors of nursing in nursing homes were asked whether they would favor tube feeding for persons described in a series of case examples. The cases varied in terms of the age of the resident (early seventies or late eighties), his or her mental status (occasionally confused or generally confused) and happiness (generally happy and contented or generally unhappy and frustrated). Results indicate that nurses were significantly more likely than physicians to favor tube feeding. There was a trend for nurses and physicians who were Catholic to favor tube feeding, and for nurses and physicians with more years of experience not to favor it, but neither of these results reached significance.

This study found that patient happiness was the strongest influence on nurses' and physicians' attitudes toward tube feeding-both nurses and physicians favored tube feeding more often for patients described as happy than for those described as unhappy. According to the researchers:

> Long-term care provides an opportunity for observing the patient's enjoyment or dissatisfaction. Enjoyment of life is quite variable in nursing home residents: some appear quite happy despite severe limitations, while others have great difficulty accepting even mild impairments. Our results suggest that staff perception of an individual's level of enjoyment plays an important role in ethical decisionmaking (229).

The study found that younger patients (early seventies) were given higher preference for tube feeding than older patients (late eighties). The patient's mental status was a significant factor in the treatment preferences of physicians but not nurses (229).

Use of the patient's mental status as a factor in decisions about whether to use nutritional support and hydration is problematic for two reasons. First is the difficulty of assessing mental status in elderly people (215). Second is the fact that impaired mental status and even coma can be caused by many factors, including malnutrition, dehydration, infections, other treatable illnesses, and medications (111,207). A comprehensive diagnostic evaluation can often identify the causes, but many nursing home residents do not receive such evaluations, thus allowing the possibility that nutritional support could be withheld on the basis of impaired mental status when the impairment was reversible.

Many legal and ethical scholars and clinicians have proposed criteria for identifying patients from whom nutritional support and hydration may be withheld or withdrawn. Some scholars and clinicans would allow withholding or withdrawal only if death is imminent or the patient is so badly deteriorated that nutritional support is physically impossible or extremely painful (22,160), and some would apply these criteria to both competent and incompetent patients (23).

Other scholars and clinicians begin with the premise that competent patients may refuse nutritional support and hydration. For patients who

are decisionally incapable or adjudicated incompetent, some would allow withholding or withdrawal of nutritional support and hydration if the patient is terminally ill and the course of his or her disease is unalterable or if the patient is in a persistent noncognitive state (sometimes referred to as irreversible coma or persistent vegetative state) (43,71,127,132,156,205). In 1986, the American Medical Association endorsed this position, stating that it is ethically permissible for doctors to withhold tube and intravenous nutrition and hydration from patients who are terminally ill or irreversibly comatose (6). Some scholars and clinicians would also allow withholding and withdrawal from some severely debilitated and irreversibly demented patients, especially when restraints are required to keep the patient from pulling out the feeding tube or catheter (118)123) 156)227).

Legal and ethical scholars and clinicians who write about withholding and withdrawing nutritional support and hydration define the categories of patients they are discussing very carefully. Many qualify their statements by stressing the importance of any previously stated wishes of the patient and wishes of the family and staff who are caring for the patient. Most add that treatment should be continued if there are doubts about the patient's diagnosis or prognosis. These careful distinctions and qualifications, however, are sometimes lost in informal discussions and media presentations, thus leaving the erroneous impression that some of these scholars and clinicians advocate widespread withholding and withdrawal of treatment from all confused or debilitated elderly patients.

Some legal and ethical scholars, health care providers, and others fear that if nutritional support and hydration can be legally and ethically withdrawn from some severely debilitated or irreversibly demented nursing home residents, the procedures will eventually be withdrawn from many residents (the "slippery slope)'). There are no data to test the validity of these fears. On the one hand, there are many problems in the general quality of care provided by some nursing homes (99)216)) and it could be assumed that decisions to withhold or withdraw nutritional support and hydration might be made too easily or too often in such facilities. In at least one State, several abuse complaints associated with withdrawal of these treatments have been investigated (136).

On the other hand, despite the many recognized problems in nursing homes, it is clear that nurses and nursing assistants in these facilities frequently succeed in sustaining the lives of very severely debilitated residents for prolonged periods, and many of these direct caregivers resist withdrawal of treatment from residents. Although no approach is foolproof, involvement of these caregivers in the decisionmaking process may provide some assurance that nutritional support and hydration are not withheld or withdrawn too quickly or too often.

An unknown but probably small number of nursing homes have formal policies for decisions about the use of nutritional support and hydration. Some nursing homes have developed limited treatment policies, but one study (135) found that few such policies addressed nutritional support. Those that did address nutritional support recommended hand feeding but did not require tube feeding if oral feeding was impossible. Some facilities require that any limited treatment order must state specifically whether intravenous fluids, TPN, tube feeding, and other treatments are to be provided for the resident (82).

Little is known about the attitudes of nursing home residents or their families toward tube or intravenous nutrition and hydration or about their role in decisionmaking. Anecdotal evidence indicates that some patients fear this form of treatment.

> **A geriatrician who works in a nursing home finished examining a confused elderly patient who was being fed with a nasogastric tube. As she turned away from the patient, she noticed another of her patients, an alert, well-oriented lady sitting in a wheelchair. The geriatrician asked this lady what she thought about the confused patient with the nasogastric tube. The lady answered that she would never want to be kept alive that way (120).**

Many elderly patients may share this lady's feeling. In discussing the attitudes of competent elderly people toward the use of nutritional support for themselves in the future, one physician

has stated definitively, "I have never spoken with an elderly patient who requested that a vegetative state be maintained by artificial alimentation" (63). Additional anecdotal evidence that some people fear artificial feeding is the observation that it is sometimes used by physicians and nurses as a threat—"If you don't eat, we will have to feed you with a tube"—in order to convince them to eat.

Family attitudes toward nutritional support and hydration vary widely. Some family members are opposed to prolonging the patient's life with nutritional support and hydration. Yet they may also feel intensely guilty about suggesting that the procedures be withdrawn (64). Because of their ambivalence, they are easily swayed by comments of the physician, nursing home staff, or a trusted clergyman. Other families have religious or moral convictions that prohibit withdrawal of nutritional support.

In nursing homes, as in hospitals, formal consent of the resident or family is generally required for TPN and "invasive" enteral procedures, such as gastrostomy tube feeding. In some nursing homes, formal consent is also required for nasogastric tube feeding. In many facilities, however, formal consent is not required for nasogastric tube feeding.

Many nursing home residents who receive nasogastric tube feeding are confused. In facilities where this procedure can be initiated and maintained for prolonged periods without formal consent, there is no incentive for careful evaluation of whether the resident is decisionally capable with regard to the procedure. As a result, nasogastric tube feeding is initated and continued for prolonged periods for nursing home residents who are assumed to be incapable of making health care decisions—that is, when they say they don't want to be tube fed, their statement is disregarded, yet they have not been adjudicated incompetent; nor has their decisionmaking capacity been formally assessed. Use of a gastrostomy tube for such a patient requires formal consent from a surrogate. For nasogastric tube feeding, even if a surrogate has been designated, the surrogate's consent is not required.

Anecdotal evidence suggests that in some cases, long-term use of nasogastric tube feeding for confused patients may reflect real or perceived difficulties in identifying a surrogate and/or a reluctance of some health care providers to consult with a designated surrogate.

Making Decisions About Nutritional Support and Hydration for Patients at Home

The decision to propose home nutritional support is usually made by the health care providers who have been managing the patient's nutritional support in the hospital. Since the patient and/or patient's family will be responsible for most aspects of the home treatment, however, their attitudes about it and their willingness to learn the treatment procedures are crucial factors in the final decision. Other important factors are the availability of medical backup for emergencies and financial arrangements that permit the patient and family to afford these expensive procedures without severe hardship (155). In addition, if the patient will have primary responsibility for the procedures, he or she must have adequate strength, manual dexterity, visual acuity, and hand-eye coordination to perform the procedures and sufficient cognitive ability to learn and remember them (101). Otherwise, family or other lay caregivers must be available to provide the procedures.

Several patient characteristics could dissuade family members from attempting to manage TPN or tube feeding at home. For example, patients who are medically unstable, bedridden, incontinent, or unable to cooperate in their care for any reason are very difficult to manage at home. Those who pull out their feeding tubes or catheters are also difficult to manage, and while some patients in hospitals and nursing homes have their hands tied to prevent them from pulling out feeding tubes or catheters, it is unlikely that many families would be willing to use such restraints on a regular basis at home.

In many cases, commercial home nutrition services are involved in the decisions about initiating home nutritional support. Some companies have formal patient selection procedures that include assessment of the patient's physical, mental, and emotional status, the availability of family support, the suitability of the home, and the availability

of storage space for supplies and equipment. Some companies also require that the patient or family demonstrate mastery of nutritional support procedures in the hospital before being accepted for home care by the company (224).

It is sometimes said that profitmaking companies and clinical enthusiasts who provide home nutrition services now encourage overuse of the procedures or will do so in the future. However, the need for active patient and/or family involvement in home nutritional support minimizes the potential for overuse. Some patients and families may decide against home TPN or tube feeding because they perceive it as complex, uncomfortable, burdensome, or invasive. Thus, one OTA contractor has concluded:

> Although it is always a possibility that in borderline situations (home TPN or enteral nutrition) could be overused by clinical enthusiasts, a natural and substantial brake on such abuse is the strong patient preference to live free of tubes and complex technology. Only when patients and their families experience a quantum leap of better health and well being will they persist with such complex endeavors (1.55).

In addition, four other factors guard against overuse of home nutritional support:

- Some nutritional support specialists who provide home care services have told OTA that patients should not be sent home on nutritional support if there is no possibility of a "meaningful" existence (155,224). Although "meaningful" is difficult to define, it is clear that these specialists reject the notion of sending patients home on nutritional support who will have very poor "quality of life."
- Nutritional support specialists are conscious of the high cost of treatment and of the concern that these expensive treatments may be overused. Several of them have told OTA that they do not want nutritional support to "be like dialysis)" which they believe is used for patients for whom it is futile or inappropriate.
- Individual physicians and hospital-based and commercial home nutrition services assume considerable legal liability for patients they supervise at home. For this reason, they are unlikely to encourage home care for patients who are unwilling or unable to learn and comply with treatment procedures or are otherwise at risk for complications associated with treatment.
- Home nutritional support is reimbursed by Medicare as a prosthetic device, as described below, and level of reimbursement is based on the supplies that are used. An additional fixed sum is included in the overall reimbursement rate for services such as teaching the patient and responding to emergencies. When patients are medically unstable or physically, mentally, or emotionally unable to comply with the necessary treatment procedures or the family is unable or unwilling to assist with treatment, more services may be needed. If these services are provided, the cost of the treatment may exceed reimbursement. If services are not provided, there is increased risk of legal liability.

Though not conclusive, these factors suggest that the potential for overuse of home nutritional support is limited at present.

Many home care patients suffer some anxiety and depression, at least in the first weeks of nutritional support at home, due to the difficulty of treatment procedures; fear about life-threatening complications; loss of the ability to eat and the social interaction that eating often entails; embarrassment about the appearance of the indwelling catheter or tube, and anxiety about the cost of treatment. Many home care patients have experienced severe illness, surgery, chemotherapy, or other treatments and may fear recurrent illness and hospitalization. Changes in body image and self concept associated with prolonged dependency on a life-sustaining medical technology can also cause anxiety and depression. Moreover, the need to rely on others for assistance may require complex adjustments in family roles and relationships that cause further anxiety. In fact, patients who are dissatisfied with their quality of life on TPN tend to develop more catheter-related complications, than patients on TPN who are more satisfied with their quality of life (70,101,158, 159,167).

Over the course of weeks or months, most home nutritional support patients, both young and old, accept the technological dependence and are proud of their ability to manage complex nutri-

tional support treatments. Anecdotal evidence indicates, however, that about one-fourth of patients, often those who are older, become depressed and doubt the value of their "technological existence." Supportive listening, small nighttime doses of an antidepressant, and frequent visits from a home nurse may cause dramatic improvement. If depression persists, some clinicians recommend presenting the option of discontinuing treatment, that, in some cases, allows patients to reaffirm their sense of control and their decision to live (155).

A final decisionmaking issue is whether expensive home nutritional support should be provided for all patients who request it or whose families request it for them, independent of any demonstrable medical benefit to them, or conversely whether utilization and/or reimbursement should be limited to patients who benefit from treatment in some defined way. Currently, the complexity of the procedures, professional attitudes, legal and financial incentives, and the lack of public funding for 24-hour home care discourage overuse of home nutritional support. In the future, however, one or more of these factors could change, and society could face demands for treatment from patients for whom the treatments are not medically beneficial. In that situation, could society deny access to nutritional support, and, if so, what criteria would be used for such limitations-would they be based on patient age, physical or mental status, or other criteria?

FINDINGS AND IMPLICATIONS

Accurate information about utilization of tube and intravenous nutrition and hydration is difficult to obtain, but industry data indicate that in 1984 about 1.4 million people of all ages received nutritional support in all settings. Elderly patients represent 40 to 65 percent of the patients who receive nutritional support in hospitals, and almost all those who receive nutritional support in nursing homes; they represent about half of those on tube feeding at home and about 20 percent of those on TPN at home.

Despite the large proportion of elderly people among patients receiving TPN and tube feeding, there has been little research on aspects of nutritional support that may differ for elderly people.

- Physiological changes associated with aging affect nutritional requirements, but nutritional standards for elderly people are not available for many nutrients. The lack of standards complicates the process of assessing nutritional status and identifying elderly patients who may need treatment.
- Changes in body composition and metabolism associated with aging suggest the need for adjustments in nutritional formulas for elderly people, but there has been little discussion of such adjustments in the clinical literature.
- Almost no information is available about indications for use, appropriate treatment procedures and formulas, or efficacy for very old people.

Research in all these areas is needed to improve decisionmaking and quality of care.

The safety, quality, and suitability for intended use of enteral formulas is another concern, Food and Drug Administration review of manufacturing, testing, and marketing practices with regard to these formulas is needed in order to determine the extent of problems and develop recommendations for solving them.

Most debate about the use of nutritional support and hydration has focused on legal and ethical issues involved in withholding and withdrawing of nutritional support and hydration from terminally ill, comatose, and severely debilitated people. Debate has centered around questions about whether nutritional support and hydration are correctly considered medical care, like the other life-sustaining technologies discussed in this report, or basic supportive or nursing care; whether they are ordinary or extraordinary care; whether they are burdensome for the patient; and whether, since all people need food and water to survive, withholding or withdrawing tube or intravenous nutrition and hydration is killing a patient or, in the case of some terminally ill, comatose or severely debilitated patients, allowing a patient to die from his or her underlying disease.

Although these questions remain, there has been a significant change over the past few years in the attitudes of many people about withholding or withdrawing tube and intravenous nutrition and hydration. Less than a decade ago, withholding or withdrawing nutritional support was rarely discussed. Now there is increasing acceptance of the idea that such support may be withheld or withdrawn from some terminally ill and comatose patients, Some people also believe that nutritional support can be withheld or withdrawn from severely debilitated and severely confused patients when the burden of treatment outweighs its benefits. Other people, including some patients, families, health care providers, lawyers, and ethicists, disagree strongly.

As of early 1987, most final court rulings in cases involving nutritional support and hydration from adult patients have held:

1. that tube and intravenous nutrition and hydration are medical treatments;
2. that competent patients can legally refuse such treatments with certain exceptions; and
3. that such treatments can be legally withheld or withdrawn from incompetent patients in carefully defined circumstances.

Prior to these final rulings, lower court rulings in several widely publicized cases—rulings that have since been overturned—had held that nutritional support and hydration could not be legally withheld or withdrawn for a variety of reasons. In several recent cases, lower courts have ruled that nutritional support and hydration could not be withdrawn. Moreover, courts in different States have set out different factors to be considered in such decisions and different procedures for making the decisions. Thus, it is understandable that physicians, nurses, and other health care providers are uncertain about the law in this area. Given their uncertainty and their general inclination to "err on the side of life," health care providers are likely to decide in favor of providing nutritional support in most cases.

Living will laws in many States distinguish between nutritional support and hydration and other life-sustaining procedures. In some States, the legislation specifies that nutritional support and hydration are not among the life-sustaining procedures that can be refused via a living will. Thus, competent adults in those States cannot direct that tube and intravenous nutrition and hydration should not be used for them in the future. The Florida Supreme Court has ruled, however, that people retain basic common law and constitutional rights to refuse nutritional support and hydration at the time the treatments are needed, regardless of restrictions in the State living will statute (62).

Questions about access to nutritional support have received much less attention than questions about withholding and withdrawal. yet several factors suggest that that tube feeding and TPN may not be provided for some elderly patients who might benefit. Many health care providers who care for elderly people have had little training in nutritional assessment, and some are not aware of the relationship between aging, nutritional status, and acute and chronic diseases. Thus, they may fail to recognize the patient's need for treatment. Lack of nutritional standards for elderly people exacerbates this problem.

Many nutritional support specialists and others believe that Medicare and Medicaid coverage and reimbursement policies discourage the use of nutritional support in hospitals, nursing homes, and in the home. Medicare's prospective payment system is believed by some to limit the use of nutritional support, especially expensive TPN, for hospital patients who might benefit from it. Data to test this assertion, however, are not currently available.

Likewise, Medicare regulations for nutritional support at home are believed by some people to limit access to care for some elderly people. Nutritional support at home is expensive. Thus, for all practical purposes, it is only available to people with Medicare or other third-party insurance to pay for it. Data to determine whether elderly people are routinely denied access to nutritional support at home as a result of Medicare regulations are not currently available.

The interconnection among Medicare reimbursement policies in hospitals, nursing homes, and in the home is a policy issue that has received little attention. While Medicare's prospective payment system is encouraging earlier discharge of hospi-

talized Medicare patients, limitations on Medicare coverage for nutritional support at home and in nursing homes may restrict access to treatment for some elderly people. Evaluation of these policies should include consideration of their impact on access to treatment across settings.

The efficacy of tube and intravenous nutrition and hydration has not been demonstrated for some diseases, and very little is known about their efficacy in elderly people. Yet the well-documented relationship between malnutrition and poor outcome suggests that critically ill and chronically ill elderly patients might benefit from increased use of these treatments and that Federal policies that discourage their use may ultimately increase the overall cost of medical care for such patients.

Concern has been expressed that severely debilitated and terminally ill elderly patients are or will be given nutritional support at home, even if it does not benefit them, because the procedures are profitable for commercial home nutrition companies. OTA has found no evidence that this is occurring. In fact, many home nutrition companies use rigorous screening procedures that exclude patients who are medically unstable, those who are confused and may pull out feeding tubes or catheters, and those for whom family support is not available. These screening procedures reflect both the companies' concern about quality of care and their legal liability for patients they serve.

The quality of nutritional support for elderly patients is diminished both by lack of information about their nutritional needs and appropriate nutritional support procedures for them and by lack of staff trained in tube and intravenous procedures in many treatment settings. As of 1984, only about 12 percent of hospitals had a nutritional support team or a nutritional support service group to assist with assessment and nutritional support treatments. Some other hospitals employ individual nutritional support specialists for this purpose, but many do not. Even fewer nursing homes and home health care agencies employ nutritional support specialists.

Lack of trained staff can result in serious complications of treatment, such as coma or death caused by failure to monitor the patient response to TPN and pneumonia or death caused by failure to check the placement of a nasogastric tube before infusing an enteral formula. Many hospitals, nursing homes, and home care providers recognize the need for increased training for staff who provide nutritional support. Yet Medicare and Medicaid policies that affect reimbursement and staffing requirements in each of the settings do not encourage the involvement of nutritional support specialists, either to provide tube feeding and TPN directly or to train others to provide them.

Very little is known about the relationship between severe dementia and eating disorders. Yet patients who are severely demented present some of the most difficult decisionmaking dilemmas, because they are usually not capable of participating in treatment decisions and because if nutritional support is initiated, they may have to be physically restrained for prolonged periods to keep them from pulling out the tube or cathether. More information is needed about the causes of eating disorders in dementia patients, their nutritional needs, the most appropriate formulas for them, the effect of nutritional support and hydration on their physical and mental status and functional ability, and the effect of withholding or withdrawing these procedures.

Typical decisionmaking practices and the role of the patient and the family in the decisionmaking process vary greatly in different settings. Decisions about the use of tube feeding and TPN at home necessarily involve the patient and family since they must learn and implement the procedures. In some hospitals and nursing homes, all decisions about tube feeding and TPN are made in consultation with the patient or a surrogate if the patient is not decisionally capable. In many hospitals and nursing homes, however, formal consent of the patient, family, or surrogate is required for TPN and tube feeding procedures that involve surgery but not for nasogastric tube feeding, which is the most widely used procedure.

Failure to require informed consent for nasogastric tube feeding is a serious concern when the treatment is expected to be long-term. Many elderly people who receive long-term nasogastric tube feeding are confused, and as indicated, such

patients are often physically restrained to keep them from pulling out a feeding tube. This combination of factors would seem to indicate a need for very rigorous decisionmaking procedures that include methods for ascertaining the patient's treatment preferences whenever possible, appointment of a surrogate decisionmaker when necessary, and periodic review of both the need for and the method of nutritional support.

In 1988, the Joint Commission on Accreditation of Hospitals will require hospitals and nursing homes to have an institutional policy for decisions about resuscitation (see ch. 5). In response to that requirement, facilities could choose to develop policies for decisions about all life-sustaining treatments, including nutritional support and hydration. Such policies would have to address any overriding presumptions about the use of tube and intravenous nutrition and hydration in the facility, in addition to the roles of patients, families, physicians, nurses, dietitians, social workers, and others in the decisionmaking process. Existing State law such as living will statutes, family consent laws, and any relevant case law (e.g., in New Jersey, the requirement that the State ombudsman for nursing home residents must investigate cases of withholding or withdrawing treatment from some nursing home residents) would have to be considered in the development of such policies.

At the least, institutional policies for decisions about nutritional support and hydration would allow patients, families, and staff of the facility to know in advance how such decisions will be made. At best, they would involve these individuals in the decisionmaking process in a way that would protect the patient right to decide but also ensure that decisions to withhold or withdraw these treatments are made cautiously and conscientiously and that they do not constitute neglect or abuse of the patient.

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