Ethics and Economics in Nutritional Support

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Introduction

Enteral and parenteral nutritional support was developed to provide sustenance to patients who ordinarily were unable to meet their nutritional needs either because of an inability to eat or an inability to digest and absorb food. Undernutrition has been associated with increased infection risk, poor wound healing, increased postoperative complications, prolonged hospital stay, respiratory, cardiac, and hepatic dysfunction, as well as increased mortality. A clinical decision must be made about the provision of both nutrition as well as hydration fluids for patients otherwise able to eat in the usual fashion.

Patients who had intestinal failure from either short bowel syndrome (congenital or acquired) or severe dysmotility disorders were doomed in the absence of parenteral nutrition. Soon after the advent of total parenteral nutrition (TPN) in the late 1960s and early 1970s, it was thought that TPN was the cure-all for many ills and it became integral to the management of the chemotherapy patient, bone marrow transplant patient, preoperative patient, burn patient, and trauma patient, among other patient subsets. It was once hypothesized that, because patients who received TPN had a significantly decreased serum cholesterol concentration, TPN might be a reasonable therapy for atherosclerotic heart disease [1].

As this therapy came under increasingly more widespread use, evidence-based medicine with regard to TPN began to evolve. It was found TPN did not increase the effectiveness of chemotherapy, improve bone marrow engraftment, result in decreased postoperative infections in only mildly or non-malnourished patients, and did not improve outcome in trauma (other than head trauma) or burn patients, and in fact was associated with significant treatment-related complications in some patients [2]. The survival rate
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Table 1. Considerations for nutritional support

- Patient’s medical prognosis and accuracy of the diagnosis
- Patient’s quality of life
- Patient’s life expectancy
- Potential benefits of therapy
- Potential risks of therapy
- Other available options
- Patient’s wishes for the use of life-sustaining therapy
- Family’s wishes if patient’s wishes unknown or unobtainable

Table 2. Criteria for determining the appropriateness of a cancer patient for home TPN [20]

- Requirement for intravenous fluid in order to maintain fluid and nutritional equilibrium
- Patients capable of self-care and spend a minimum of 50% of their waking hours out of bed
- The patient is able to physically as well as mentally and emotionally stop, start, and control their TPN
- Survival of ≥3 months is anticipated
- The patient is aware of the diagnosis and prognosis, and can therefore make an informed decision as to use TPN
- There is no alternative to TPN

for patients with malignancy who receive home TPN was 32% in an Italian study, with satisfactory social activity achieved in only 25% of these patients [3]. Survival is only 15% for patients with metastatic disease who receive home TPN [4], and the length of survival is most often 2–3 months or less [5–7]. Home TPN does not improve quality of life for the majority of cancer patients [7], although quality of life may be improved for those patients who are more functional at baseline and in whom more prolonged survival is anticipated [3, 6]. Specific criteria have been proposed to identify cancer patients who might be most likely to benefit from home TPN (table 2) [8]. Similarly, enteral nutrition (EN), administered by enteric tube in demented patients has not been demonstrated to improve survival, prevent infection or prevent pressure ulcers [9].

Should Nutritional Support Be Initiated?

The decision to initiate nutritional support should be based on the potential risks and benefits in conjunction with the patient’s and, to a lesser degree, the
family’s desires. These desires may be tempered by religious and cultural beliefs. Regardless, it must be realized that the goals of nutritional support may evolve and change during the course of a given patient’s illness. It is unclear whether patients are actually treated with nutritional support or simply maintained. Is nutritional support a treatment in and of itself? If not, can it be considered to have treatment attributes if its use contributes to the treatment of underlying pathology, or is considered a part of the success of other therapies (table 3)?

The initiation of nutritional support should be accompanied by informed patient consent, although such consent need not be in writing. This consent requires the patient to have an awareness as well as an understanding of their prognosis, the requirements of the proposed therapy, the potential for success with nutritional support and what that ‘success’ entails, and the possible risks inherent with the therapy. This principle of beneficence weighs the benefits of an intervention versus the burdens produced by such an intervention. The principle of beneficence requires the patient to be informed of the potential medical benefits and risks prior to initiation of this nutritional support; ‘every human being of adult years and sound mind has a right to determine what shall be done with his own body’ [10]. If the patient is not properly informed, he or she is incapable of making an informed consent [11]. The potential for benefit must be discussed in terms of improved survival, improved quality of life, comfort, or correction of metabolic abnormalities that have a material impact on the quality, appropriateness, and success of the medical care rendered. According to the Helsinki accords a physician is free to propose therapy, but not necessarily to use such therapy. Informed decisions about what may be justified in a research setting are not necessarily the same as what is required in a clinical setting.

A physician who cannot explain or will not explain the unbiased risks and benefits should remove themselves from the consent process. Notwithstanding the explanation of the consent, the physician is free to render an opinion or advise to the patient. That said, it is important to differentiate opinions,

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Table 3. Arguments for initiation or continuation of nutritional support

- Nourishment is within the scope of minimal care and is required regardless of how hopeless recovery may be
- Dignity required feeding
- Nutritional support may be provided in a noninvasive manor
- Nourishment, provided by nutritional support, is not medical therapy
- Withdrawal of nutritional support will precipitate painful and agonizing death from starvation and/or dehydration
- Nourishment via nutritional support allows life to continue until the underlying illness runs its natural course
which may be construed by the sequence of discussion or the emphasis the physician places on a particular modality, from concealment. Concealing information to promote certain treatment options is unethical. There is no evidence that concealing what admittedly may be a poor option provides benefit to the patient. In a study of 421 randomly selected, competent patients living in 49 different nursing homes were surveyed about feeding tubes. 24% of the eligible patients refused to participate, but only one third of the 379 patients who completed the survey stated they would agree to feeding tube placement if they were unable to eat sufficiently, and 25% of those who agreed changed their minds when told that feeding tube placement and use might involve restraints [12]. The associated use of restraints is often a required, but has a negative influence on the quality of life in the cognitively impaired patient [13]. It was not made clear whether tube feeding would have been via a nasogastric tube or percutaneous endoscopic gastrostomy (PEG). Males, African-Americans, absence of a living will, and no previous discussions of life-sustaining therapy with family or staff were all associated with a greater likelihood to prefer tube feeding [12]. Similarly, in another study, elderly patients who initially indicated that they wanted cardiopulmonary resuscitation in the event of cardiac arrest rescinded their wish when told of the poor outcome of attempted resuscitation [14].

Physicians and family must be careful to avoid intrusion on which, by all rights, is the territory of the patient in question. This is the concept of self-determination. In cases where the value of nutritional support is unclear or undefined, a limited trial may be considered, with efficacy to be evaluated and goals to be potentially reevaluated. Nutritional support is not mandatory when it is burdensome or of no proven medical value [15]. TPN is associated with numerous potentially life-threatening complications that include bleeding, infection, thrombosis, metabolic abnormalities, hepatic failure, renal disease, and osteoporosis [16]. EN is also associated with numerous potentially life-threatening complications, including infection, perforation of abdominal vis-cera, aspiration, metabolic abnormalities, and diarrhea and dehydration [17]. One does not omit feeding in a conscious attempt to cause death, although death may ultimately result. Therefore, withholding nutritional support is not a decision to kill by lethal omission.

PEG or home TPN are seldom indicated in the patient with advanced cancer associated with a significantly diminished performance status, or in those patients whose unresectable disease is unresponsive or not judged appropriate for radiation therapy or chemotherapy. In these cases, the patient will not be able to adequately use the nutrition even if provided, and there is little or no chance quality of life will improve and a not insignificant chance that quality of life may be further decimated. In a study of 135 nursing home residents who had a feeding tube placed because of severe cognitive impairment, there was no increase in survival [18]. The only determinants of survival were the
patient’s underlying medical condition, advanced age, and do not resuscitate status. Other studies have shown no benefit of EN support on the healing of pressure sores in similar patient groups [9]. Rabeneck et al. [19] suggested that the initial determination of whether a patient should have a PEG placed is to determine whether their cachexia-anorexia is due to metabolic alterations that will be unresponsive to nutritional support. They proposed a decision-making algorithm for PEG tube placement (fig. 1). These authors indicated that the physician is under no obligation to place the PEG if no significant physiological benefit is anticipated. PEG tubes and central venous catheters are often placed inappropriately because of unrealistic expectations on the part of either the health care provider or the patient, or both. Issues of perceived improvement in quality of life and improvement in outcome of malnutrition without regard to the underlying disease process, no matter how unrealistic or impractical, may cause considerable confusion among patients and their families and support.

Appropriate indications for PEG include dysphagia secondary to reversible disease, incurable disease with survival potential, loss of the ability to eat, primary neurological disorders with the likelihood of prolonged survival and improved quality of life, severe upper gastrointestinal motility disorders (often for decompression) or obstruction, and growth failure (children). It should be noted that PEG does not prevent aspiration or aspiration pneumonia [20, 21].

<table>
<thead>
<tr>
<th>Clinical category</th>
<th>Clinical guideline</th>
<th>Ethical rationale for guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexia-cachexia syndrome?</td>
<td>Yes</td>
<td>Do not offer PEG</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patient unable to make use of nutrients</td>
</tr>
<tr>
<td>Permanent vegetative state?</td>
<td>Yes</td>
<td>Offer and recommend against PEG</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patient unable to experience any quality of life</td>
</tr>
<tr>
<td>Dysphagia without complications?</td>
<td>Yes</td>
<td>Offer and recommend PEG</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patient unequivocally benefits from PEG</td>
</tr>
<tr>
<td>Dysphagia with complications?</td>
<td>Yes</td>
<td>Discuss no PEG vs trial of PEG</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patient equivocally benefits from PEG and potential exists for loss of quality of life</td>
</tr>
</tbody>
</table>

**Fig. 1.** Decision-making algorithm for PEG tube placement. From Rabeneck et al. [19]. Reprinted with permission.
The Role of Morality, Religion, and Patient Self-Determination: Who Should Not Receive Nutritional Support?

**Morality**

Some regard feeding as a moral and emotional commitment rather than a medical therapy. The provision of food and fluids has often been associated with nurturing and caring. It has been widely stated that one cannot allow a patient to ‘starve to death’, or to ‘allow the patient to die of thirst’. Food intake is also often viewed within a social context, and is associated with pleasurable phenomenon including taste, smell, and socialization according to Lipman [22]. However, consumption of continuous and non-orally introduced food and fluid can hardly be seen as socially normative. Does eating require the monitoring of electrolytes, blood urea nitrogen and creatinine? Does eating require the flushing of the mouth? Does eating require a permanently attached fork to the mouth in order for nourishment be delivered? Lipman [22] has referred to this as non-volitional, forced, invasive delivery of artificial, limited, and fixed substrates associated with finite morbidity and mortality. Some might also add that if one does not want extraordinary care, then why even come to the hospital?

What is the definition of the life that is being sustained? Life has different meanings to different people. It may be a single cell, or it may be defined in the context of a functioning groups of cells, or at a higher level including other living creatures or a society where each life plays a unique role (fig. 2). When does life cease? Is it when one part of society, some tissue from an organism, or some cells from tissue become separated, lost and perhaps die?

Kantian ethics considers the act itself is intrinsically right or wrong regardless of the outcome. This concept is based on the idea that what happens in life is often governed by chance and circumstance (i.e. a lucky shot in billiards) and therefore, the motivation for the act becomes the differentiating factor. Therefore, nutrition should be provided for moral reasons and omission or withdrawal would be considered unethical. Utilitarian ethics suggests the means to the end are not important, it is the end result that matters most. Therefore, no act is intrinsically good or bad, but the goodness or the badness, and hence, the morality of an act is determined from the outcome. If happiness or a positive outcome is achieved, the act would be considered ethical and moral.

**Religion**

Historically, Judeo-Christian litany has proclaimed the sanctity of human life. The physician is the healer and woe is thy name who seeks to end life prematurely by omitting or withdrawing life-sustaining nutrition and hydration. In Judaism, it is of the utmost importance to preserve and sustain life. However, in cases of terminal illness, where therapy would be expected to increase the patient’s suffering or be considered futile, the patient may be
entitled to reject such therapy in advance just as with other therapeutic interventions [23]. In general, even Orthodox Judaism argues against interventions that prolong suffering and impede dying [23, 24]. In Judaism, the physician may be permitted to use heroic methods to save and prolong life, but may not be required to do so. Some, however, consider tube feeding basic care that may not be rejected; other Jewish theologians point out that God provided the materials and know-how to develop feeding catheters which therefore should be used to prolong life whenever necessary. However, it must be realized that the development of today’s technology of artificial feeding was unforeseen by our ancestors.

In Catholicism, extraordinary care is optional and the patient may refuse it, although ordinary care may not be refused. Sometimes the definition of extraordinary must be viewed operationally, or within the context of a particular situation. For example heart valve replacement may be considered ordinary care in an otherwise healthy high school student, but would be considered extraordinary in a debilitated 90-year-old individual. Proportionate care has been defined as that capable of providing a reasonable chance for a substantial and sufficient benefit as to justify the risks (including pain, expense, and inconvenience) and complications inherent in such therapy. Otherwise, care is known as ‘disproportionate’ when it does not offer reasonable hope of benefit, and patients may refuse it. Extraordinary care is disproportionate care that may not be justifiable in a risk-benefit analysis.

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**Fig. 2.** The definition of life and death. Adapted from Belgumd et al: J Religious Health 1980;28:125–137.
In general, religious, ethnic, and cultural beliefs and preferences should be respected when the initiation or withdrawal of nutritional support is considered, especially when such therapy may be life-sustaining. For example, Americans place a high value on individual autonomy, the individual’s ability to make decisions for themselves. However, in order to make such decisions, the patient must be educated about their disorder, treatment options, and potential outcomes. In other cultures, such as Japan and other Asian countries, as well as Mexico, it is the family that bears the brunt of the decision-making process, and the patient may not even be aware of a terminal diagnosis and prognosis.

Self-Determination and Medical Decision Making

When patients are near death and are given the opportunity to refuse nutritional support, the majority do so [25]. Studies have shown that, at least in some circumstances, physicians may underestimate patients’ quality of life when compared to patients’ own ratings [26]. Capacity refers to an individual’s ability to make an informed decision as assessed by health care providers rather than a judge. The physician should form an opinion about a patient’s capacity to provide an informed consent. If an individual does not have the capacity to make a medical decision about their care, a decision-making algorithm is displayed in figure 3. If the patient is mentally incapacitated, an appropriate proxy must be identified. If a patient has the capacity of make an informed decision, the principle of autonomy requires respect for that decision.

The combination of patient refusal for one life-sustaining therapy such as surgery, but agreement for other life-sustaining therapy such as nutritional support should not be considered incomprehensible, but should be respected by the health care provider. The caveat is that the patient should be properly educated in order to make such a decision.

In cases where the patient is able to make an informed decision with regard to treatment, a distinction must be made between refusal of nutritional support because of unpleasant side effects, and refusal of such therapy because quality of life will not be improved in the long-term. It also may be difficult to determine when depression is sufficiently severe as to impair decision-making capacity.

Some physicians consider TPN and EN, as well as hydration to provide a basic human need to avoid starvation and dehydration. Views among patients and physicians and other medical personnel may vary across cultures and nationalities. For example, patient self-determination is of utmost importance in the United States where given the choice, many terminal patients may choose to forgo life-sustaining therapies, including artificial nutrition. This decision process is supported by the Federal Patient Self-Determination Act. In other cultures, such as Japan, it is not customary to inform the patient of a terminal diagnosis and therefore, the patient may wish to
continue therapy. In the situation of a terminally ill patient (a 65-year-old businessman with metastatic gastric cancer with a 1-month expected survival) who is unaware of his diagnosis, 67.5% of surveyed multi-specialty Japanese physicians would provide TPN for malnutrition although only 36% of those surveyed would want such therapy for themselves in a similar situation (and only 5% of Japanese-American physicians; fig. 4) [27]. On the contrary, only 33% of Japanese-American general practice and internal medicine physicians would recommend TPN to treat malnutrition in a terminal condition. 36% of the Japanese physicians indicated they would ignore the patient’s request to withdraw TPN if the physician thought it necessary, although only 6.5% of Japanese-American physicians would do so. For patients in a persistent vegetative state during which the patient has eyes-open unconsciousness, periods of wakefulness and physiologic sleep-wake cycles, but shows no evidence of self- or environmental awareness, opinions of American neurologists and Medical Directors are even more clear-cut: 89% of 490 respondents in a national survey believed the withdrawal of
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**Fig. 4.** 65-year-old businessman with metastatic cancer and 1 month expected survival. Adapted from Asai et al. [28].

artificial nutrition and hydration from such patients was ethical [28]. A survey of 580 internists in the USA revealed similar opinions [29]. It has been estimated that the cost of providing futile care for these patients even some 10 years ago was USD 1–7 billion/year [30]. However, treating physicians may often find it difficult to realize and understand the value of an individual to their family and friends, even in a persistent vegetative state.

**What Is the Goal of Nutritional Support in the Terminal Patient?**

The history of nutritional support in the terminal patient is similar to cardiopulmonary resuscitation; it has been tried in virtually every patient who died, despite having been invented for specific, reversible conditions, and was deemed unsuccessful in most [31]. Patients with terminal illness are often comfortable with very limited food and water intake [32]. TPN and EN may adversely affect the body’s normal adaptation to starvation [32–34]. Anticipation of a poor outcome does not engender the treating physician to act to prevent such an outcome. One must consider the fact that nutritional support itself, especially in the patient in whom the medical prognosis is not expected to reasonably improve, may be a form of torture. In the absence of evidence-based medicine to confirm a substantial benefit of nutritional support in a terminally ill patient (quality of life included), rather than providing the patient the option to refuse therapy should be replaced with a question to the physician provider: why was nutritional support proposed in the first place? The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical Research expressed the principle that physicians are not required to provide futile therapies [35]. Futility has been medically
defined as a treatment that fails to improve the patient's prognosis, comfort, well-being, or general state of health for which there is no possibility of a meaningful recovery [36]. Actually withholding nutritional support may enhance patient well-being and comfort in some cases, most notably those who are terminally ill.

A primary goal of nutritional support should be an improvement in the patient's quality of life. However, quality of life is a value judgment and as such lacks a common definition so that a value is difficult to assign to improvements or decrements. There may also be inconsistencies in the interpretation of quality of life; there exist both objective and subjective components. It is difficult to judge quality of life in another without interference from one's own bias. Therefore, decisions by surrogate decision makers with regard to initiating or withdrawing nutritional support in order to effect improved quality of life may be invalid.

**Nutritional Support in the Developmentally Disabled and the Non-Terminal, but 'Vegetative' Patient**

Although the medical literature contains references to a number of cases where patients arose from seemingly comatose, vegetative states, the general medical consensus is that a persistent unconscious condition is irreversible and there is no reasonable likelihood of recovery of cognitive brain function. Apply the concept of 'beyond reasonable doubt'. However, notwithstanding the evidence, the decision to withdraw or withhold nutritional support should be made on an individual case-specific basis.

The decision to initiate or to withdraw nutritional support in the patient lacking the capacity to make such a decision themselves, rests on the relative weight assigned to benefits to the family such as prolonged life versus the burdens on the patients such as complications. For example if the family wants mother to live as long as possible, complications from nutritional support may be viewed as acceptable consequences. Regardless, the nutritional plan should have a commitment to discontinue treatment if anticipated measurable physiological outcomes are not achieved if appropriate and sufficient nutritional support has been provided for a sufficient length of time. The informed consent for the delivery of such nutritional support should include the prospect of medical uncertainty.

The developmentally disabled may never have had the capacity to make a decision about their medical care. Therefore, it is difficult for surrogate decision makers with power of attorney to make decisions based on what the patient may have wanted. However, such patients do have an interest in having a minimum of suffering in relation to treatment benefits and to be as pain-free as possible.
Can Nutritional Support Be Withdrawn?

Is there a difference between failure to initiate therapy and an action to discontinue therapy? Is shutting off tube feeding or TPN similar to shutting off the heat or air conditioning or oxygen delivered via nasal cannula? Some studies have shown that physicians are often reluctant to withdraw therapy even when the risks outweigh the potential benefits [37]. Professional organizations such as the American Medical Association have issued guidelines that ‘Artificial administration of nutrition and fluids is a life-prolonging treatment. As such, it is subject to the same principles for decisions as other treatments’ [35].

Most would agree that there is no moral obligation to continue medical care at all, including nutritional support, when inevitable death is imminent and continued treatment would only prolong life under such circumstances. However, there is a moral obligation to care for, including medical care, and to provide nutritional support if necessary, for those patients who may otherwise be incapacitated, are helpless, or even chronically ill. However, this moral obligation does not necessarily exist towards patients who are in a persistent vegetative state or in whom no possibility of meaningful recovery exists or in whom a terminal illness has been diagnosed with a prognosis that includes either a minimal survival time or minimal quality survival time. Medical treatment, including nutritional support if necessary, is appropriate in order to provide some relief from suffering or an improvement in the underlying disease state that may result in improved quality of life (table 3). Withdrawal of nutritional support should be accompanied by ‘comfort care’, which includes appropriate pain management. It might be said that comfort care avoids abandonment and a human bond so that other care may be morally withdrawn. However, there cannot always be sufficient evidence that the patient is suffering pain from nutrition support or its delivery.

Legal Considerations

Laws supply secular morality that may often cross cultural boundaries. Laws vary between countries however, and judgments from one country cannot necessarily be applied as precedent for another. Recent court cases in both the United States and the United Kingdom have generally upheld the withdrawal of nutritional support in severely demented patients with essentially no chance for recovery and for whom no benefit from nutritional support was demonstrated [38]. Withholding and withdrawal of therapy are legally equivalent.

Competence and capacity for judgment refer to a given patient’s ability to exercise good judgment and make an informed decision on their own behalf. Competence is actually a legal definition that defines an individual’s perceived ability to make appropriate decisions. Competence or incompetence are not
all-inclusive. For example, an individual may be incompetent to handle their finances, but competent to make medical decisions.

Laws generally govern the mechanism for transfer of decision-making power. An advanced directive, such as a living will, takes precedence over family relationships. If a proxy becomes involved they are asked to provide substituted judgment – to decide as best they can how the patient themselves would have decided if he or she had been able.

In the United States, advance directive laws are in affect in each state. These statutes enable each patient to voice their decision about life-sustaining therapies prior to becoming incapacitated and unable to render such opinions, although patients are often not instructed to comment on more specific items such as nutritional support. The United States Supreme Court has ruled the provision of nutrition and hydration are medical treatment and as such, may be legally withheld or withdrawn if there is an appropriate medical and ethical situation [39]. In addition, the withdrawal of life-sustaining therapy has been made legally distinct from homicide since 1976 in the United States [40]. However, in such countries as Germany, the withdrawal of nutrition in patients suffering from terminal illness may be considered active euthanasia unless death is imminent [41], and invokes the potential of civil or even criminal liability [42].

So-called ‘living wills’ permit an individual to provide advance directives should they become incapacitated. Nutritional support should be specifically addressed in advanced directives and living wills. Such directives may include the disallowing of certain aspects of treatment and may also include provision for a proxy decision maker, the latter including the use of durable powers of attorney. These directives allow the individual to identify an individual who has intimate knowledge of their desires who can make health care decisions in the event the individual is unable to make such informed decisions. Incumbent on such decision making is the obligation that the decision maker should express the desires of the patient as best they can rather than their own desires. Most, if not all states require that hospitals, nursing homes, and other similar institutions develop and use a policy covering advance directives.

**Nutritional Support in Children**

Parental consent is required for medical treatment [43]. Parents are responsible to make healthcare decisions about their children. Courts have consistently upheld parents’ rights to serve as surrogate decision makers for their children indicating that they are better placed to represent the child’s best interests. Courts have held that as the appropriate decision makers for the children, parents may refuse life-sustaining therapy as long as such refusal does not constitute neglect [44–46]. However, parents are not given
carte blanche as society has established protections designed to prevent child neglect. ‘Baby Doe’ amendments in 1984 to the 1973 Federal Child Abuse and Neglect Prevention Act mandate that infants with severe life-limiting handicaps still receive appropriate nutrition and hydration under all circumstances, although the word ‘appropriate’ does allow some latitude in interpretation [47, 48]. Physicians can invoke the power of the state to initiate or to continue treatment, but only when such treatment is clearly beneficial to the patient and such treatment is considered the appropriate standard of care. In that situation, refusal of treatment would be grounds for medical neglect. However, both ethical and legal consensus has emerged that concludes nutritional support and hydration may be omitted if justification can be made [49–51].

Economic Considerations in Nutritional Support

One may question whether it is ethical to consider costs of nutritional support to either the individual or society in terms of money and resources. However, economics can be defined by a variety of cost analyses (table 4). In 1990, the yearly cost for hospital-based TPN in the USA was USD 6 billion [52]. Trujillo et al. [53] reported that 23% of 209 inpatients begun on TPN at the Brigham and Women’s Hospital in Boston over a 5-month period had alternative means of nutritional support and 15% were not indicated under the American Society for Parenteral and Enteral Nutrition (ASPEN) guidelines [54]. Avoidable charges (although not costs) for preventable TPN days were USD 510,746 when extrapolated to a full year. 35% of patients had short-term TPN use (<5 days) for which risks may be increased, but the potential benefit is nil.

National guidelines governing home EN are present in 3 European countries and guidelines for home PN in 4 European countries [55]. Guidelines are present in the United States, but unlike Europe, most patients are not cared for at centers of expertise. Interestingly, Medicare, Medicaid, and private insurance companies in the United States support the financing of hospital-based as well as home nutritional support, but have shown no interest in assuring that patients receive the highest quality and cost-effective care. Rankings of hotels, airlines, football teams, schools, and hospitals are commonplace in American, but there is no ranking of homecare agencies or of professionals involved in the delivery of homecare. In fact, nutrition as a whole is a completely unregulated field. Medicare has specific guidelines for the indications of both home TPN and home EN, otherwise financial coverage is not provided. For TPN, these include: (1) permanent (≥3 months) disease whereby small intestinal absorption or transport is impaired; (2) enterectomy within the last 3 months leaving ≤1.5 m of residual small intestine; (3) with an oral/enteral intake of 2.5–3.0 liters/day, enteral losses are ≥50%
and urine output is ≤1 liters/day; (4) energy needs are 25–35 kcal/kg/day; (5) mechanical small bowel obstruction and surgery is not an option, or (6) 10% weight loss over last 3 months, serum albumin concentration is ≤3.4 g/dl, and fecal fat losses are 50% of intake, although exceptions can be granted for less severe malabsorption. For EN, this includes: (1) permanent (≥3 months) disease or inability to swallow or get nutrients into the small intestine, and (2) a disease that impairs digestion and absorption of an oral diet where the patient is unable to maintain weight and strength from an oral diet. Tube feeding has not been validated for efficacy in demented nursing home patients. Despite that, it has become commonplace and in addition, undue emphasis should be given to staff convenience. Randomized, controlled clinical trials of the efficacy of tube feeding in the demented nursing home patient should be funded and undertaken. Few studies have used actual costs rather than charges or published wholesale charges, the latter of which are subject to negotiated contracts. In addition, estimates for the cost of parenteral nutrition and EN generally have excluded the costs of hospitalization and treatment for complications related to these therapies. For example, patients are typically hospitalized 3–5 days/year because of complications related to home TPN; hospitalization may be required to treat complications of home EN, but is much less common [56]. The cost to an individual’s lifestyle should also be considered when determining economic costs (table 5). This includes physical and emotional problems stemming from nutritional therapy, sleep deprivation, loss of social prestige, changes in employment and leisure activity including exercise and travel, and time involved in required self-care.

Nursing home costs of care are higher for patients not tube fed versus those that receive tube feeding [54]. Much of the increased cost is caused by the increased nursing staff and nursing assistant time to feed patients; food costs were similar between groups. Total costs including hospitalization and treatment of tube-feeding complications resulted in substantially increased overall costs in the tube-fed group. However, the brunt of these costs were
not born by the nursing home. In addition, in at least 32 states, government reimbursement for the tube-fed patient is substantially greater than for the non-tube-fed patient [57]. Therefore, it appears that a financial incentive exists for nursing homes to require a PEG prior to acceptance from an acute care facility. In addition, state regulatory agencies often use weight measurement as a surrogate sole measure of nutritional status and therefore nursing

Table 5. Example of items in cost-benefit categories for home enteral nutrition

<table>
<thead>
<tr>
<th>Cost</th>
<th>Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct</td>
<td>Nutritional product Resources not spent on hospitalization costs</td>
</tr>
<tr>
<td></td>
<td>Feeding set or syringe Room</td>
</tr>
<tr>
<td></td>
<td>Pump and pole rental Monitoring services</td>
</tr>
<tr>
<td></td>
<td>(if continuous drip)</td>
</tr>
<tr>
<td></td>
<td>Tube site dressing supplies Other costs</td>
</tr>
<tr>
<td></td>
<td>Nurse visits for instruction Reduced risk of nosocomial complications</td>
</tr>
<tr>
<td></td>
<td>and follow-up</td>
</tr>
<tr>
<td></td>
<td>Transportation to physician Cost to payer is less (assuming family or</td>
</tr>
<tr>
<td></td>
<td>office for follow-up patient able to provide own care and</td>
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<td></td>
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<tr>
<td></td>
<td>Person time for stocking Expense to patient may be less or more</td>
</tr>
<tr>
<td></td>
<td>and delivering the depending on coverage plan benefits</td>
</tr>
<tr>
<td></td>
<td>product and supplies</td>
</tr>
<tr>
<td></td>
<td>Procedures for tube replacement (radiology, endoscopy)</td>
</tr>
<tr>
<td>Indirect</td>
<td>Time off work for family Patient or family may be able to return</td>
</tr>
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homes are pressured to maintain ‘normal’ weight and to prevent weight loss via tube feeding.

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Discusion

Dr. Bozzetti: I have a short comment and a question. The comment is that in my presentation I omitted a point that you have stressed which is when and how to withdraw nutritional support in this situation. With reference to the cancer patients, I think that the correct policy is to discuss the potential indications for nutritional support and for withdrawal of total parenteral nutrition (TPN) at the same time. I do this when I propose TPN at home, and the reasons for doing this is that if we are not able to reach our endpoint after 2 weeks or 2 months of nutrition, we have already agreed earlier that if there is no evidence of efficacy or benefit of TPN, we are authorized to withdraw the nutritional support. So this is a very important point when faced with competent patients or the family to discuss this point before starting home TPN. I was impressed by the article published in the Lancet by Chochinov et al. [1] a few years ago in which they analyzed the living wills of 168 patients. They were able to show how the living will changes during the day, during the week and during the month. So I question how we can rely on the living wills made by persons who are not ill when they make this decision; perhaps when they are sick they will change their ideas as sick people also change their ideas in the different periods of their disease.

Dr. Buchman: Individuals are always free to change their living wills, but I have not had the experience of seeing this happen very frequently. In fact in our hospital it is required when a patient enters the hospital that there is some advanced directive noted on the front of the chart as to whether these patients, once they had cardiopulmonary resuscitation (CPR) for example, are to be transferred to an intensive care unit, this sort of thing. Of course one of the issues that we also have to be careful of is, for example, an individual who comes to the emergency room with a broken leg and says ‘just kill me, let me die, I can’t take this pain anymore’; well he really doesn’t want to be dead. But I think the living will still has to be respected because regardless of whether it changes a 100 times that is the patient’s decision and the most current decision is the most current decision that we have to respect. When they complete a living will, the medical issues need to be discussed with these patients by a health care provider who is duly informed so that the patients know exactly what it is that they are agreeing to or what they are not agreeing to, and the living will can also be very specific. For example it might allow a patient to be on a ventilator but not allow CPR, it might allow dialysis but not CPR and a ventilator. There are various combinations, and again this is the patient’s will and we as physicians have to respect that. It is a legal document and so it is not really up to us to determine whether it is rational or justified since it is a legal document. For us to determine if something is rational or justified such as a living will, I think is also somewhat inappropriate because that is a value judgment that we see only with our own eyes, and therefore it is by definition biased.

Dr. Thomas: I just want to clarify a couple of things about the living will which I think will be helpful for those of you who may not be familiar with it. The legislation that covers the living will is convoluted and typically crazy. It requires that when a patient is admitted to a hospital he/she will be asked whether they have a living will or not. It does not require that they have a living will, and so there is a form that is filled
out by the admissions clerk buried in the chart that most physicians never see, and most patients in fact don’t have a living will. In the geriatric population we find that if you do surveys and questions you find very few people over the age of 65 or in nursing homes that want a living will or will fill one out even if help is provided. The law also requires that the hospital provide assistance to anyone who wishes to complete a living will on admission to the hospital. In fact that rarely happens. The second issue of the living will is that it only applies when two physicians determine that the patient is hopelessly, terminally and irreversibly ill. So, even though we typically view it as describing what people would like to have, in fact it does not take effect until the physician determines that there is no hope of recovery. Therefore, it only springs into effect at that late, late, late junction. The advanced directive laws in the United States are different; they allow someone to appoint a surrogate decision maker in case they can’t make a decision themselves. The living will is often used as a sort of guidance, but in fact most Americans don’t have a living will and most Americans don’t want to make a living will, and it is certainly not a requirement at admission.

**Dr. Buchman:** I would certainly agree with that although I would suspect that the number of individuals in the United States with living wills have significantly increased over the last few years, because there has been a public effort to educate individuals about that. Certainly when they come to the hospital for the first time perhaps they may actually receive their initial education about it at that point.

**Dr. Bowling:** I have a statement and a question. In English law we don’t provide for surrogate decision makers and it is actually down to the senior clinician involved; unlike Scotland where surrogates are involved. The question actually goes back to this conversation on advanced directives. I accept that they can be quite specific, but it is certainly my experience that they are often very nonspecific and are drawn up by an individual with or without some legal advice but usually not with medical advice. So, for example, you might be presented with an advanced directive that says ‘if I am rendered incapable I do not wish to receive nutritional support’. Now the problem that that can put you in is if a patient comes in with a stroke and you know that there may be a reasonable chance of recovery, perhaps several weeks down the line, but you are faced with an advanced directive saying I do not wish to be fed. What do you do? Do you try to persuade the family that actually this advanced directive is perhaps not appropriate, and then you might be sued if the patient does recover and has found out that he received nutritional support. I think it is very difficult.

**Dr. Buchman:** That is a very difficult question and again the world of ethics is not to provide answers, it is actually to provide questions, and that makes my talk much more different from the others that will be presented. I think clearly all these issues are on the table, but one of the things that as health care providers we need to be careful of is not to allow our own value judgments to interfere with our recommendations for the patients; our job is to provide them with the data and they then make the decision. As I mentioned yesterday, I think there is hardly a patient that I can’t convince to have a gastrostomy tube at some point, but it may take a few visits. It all depends on tact and how it is explained.

**Dr. Bowling:** But it can be pretty tough on families to put the decision making issue into their hands. It is a very difficult emotional and traumatic time for them, and I think we have got to be careful that we are not just passing the buck because we don’t want to get into difficult situations and difficult decisions.

**Dr. Buchman:** I agree, but one of the things you also have to do is to support whatever decision the family makes because that allows the family to have some feeling that they have made the right decision, when in fact there may be no right or wrong decision. But you have got to support their decision. There is a difference between supporting their decision and making the decision for them. Often times you
will be presented with a family who wants you to make the decision because either
they don’t know or more likely they don’t want to actually make the decision them-

Dr. DeLegge: I have two questions for you, ethically or I guess legally with regard
to home parenteral nutrition. For someone who is about to go home and has not been
on home parenteral nutrition before, do you think that the informed consent process
should be more formal, meaning rather than just an explanation to the patient? Similar
to other therapies that you might do, for example a liver resection, the consent process
would be a lot more formal, there would be a lot more said about it, it would be writ-
ten and very detailed. That was question one. The question two is in regard to one of
the situations that I always have the most difficulty with; it is a rare instance but it
happens that a family wants to withdraw nutrition support, that I may or may not
agree with. In those situations do you see any role for a hospital-based ethics com-
mittee to help and evaluate the situation from outside?

Dr. Buchman: I will answer the second question first. There are certainly times
when, like you, I have also perhaps disagreed to some degree or even completely with
the families’ desires, and that is a situation where you need to remove yourself from
the decision-making process. I often start by getting a second opinion from a col-
league, and certainly a hospital-based ethics council is also appropriate, but remem-
ber that an ethics council is not necessarily going to provide you with an answer. They
are going to provide you with the appropriate questions that you and the family and
the other providers need to think about. The family and team meetings can also be
useful for everyone to have a chance to voice their opinions and disagreements, and
that would include the family and in many cases the patients themselves, the nurse,
perhaps the dietician, and whoever else is involved in the patient’s care so that a con-
sensus opinion in terms of the direction of treatment can be derived. I personally hate
those sorts of things because they normally take at least an hour away from your usual
work, but sometimes there is no alternative. In terms of your first question with the
consent for nutritional support; many of you may know that in the United States the
regulations in the last couple of years in health care have become overwhelming and
much of this has come about because there were some indignities involved in terms of
health care and health care research; there were patients at John Hopkins and other
places who were in experimental studies to which they had never even consented to
be in. Similar things went on here 50 years ago, perhaps even to an almost similar
degree. These are very isolated events, but unfortunately what has come out of those
is a whole set of requirements and privacy statements and so forth that has made
actually doing clinical research extraordinarily difficult. In fact even taking care of
patients is difficult. We can’t even talk to a consultant now and tell them about the
patients they are about to see unless the patient has actually signed a document and
that document is faxed to the physician. A patient can e-mail me with a question and
legally I can’t even e-mail an answer back unless they fax a signed consent form allow-
ing them to communicate by e-mail, even though they initiated the contact. So I shud-
der at the idea of adding another written document to the overwhelming number of
documents now, but I think it probably would be better then. Perhaps it is not inap-
propriate actually to have a specific document for an informed consent for nutritional
support itself just as you would for a surgical procedure or endoscopy for example,
but I think it is important for these patients because they are very few. The patients
who require home TPN for example are almost 40,000 in the US but probably there
are around 5,000 to 10,000 requiring this on a permanent basis. These patients should
be taken care of by perhaps 10 centers across the US, as much as they are in France and other countries. Europe seems to be backing away from that, but I think once the health care providers have a particular expertise in nutritional support, for example, they are uniquely qualified in order to provide the patient with information such as the cost and benefits that they may achieve. In my opinion, I think that is even more effective than having a signed consent because patients can sign anything put in front of them, but its value is only how well they understand the consent and how well it is explained to them; it also reflects whether a level of coercion is involved. I don’t do what we call open colonoscopy. Screening colonoscopy has become a big thing in the United States, it is a money-maker for the gastroenterologists and a big thing for patients. Often an internist will simply check colonoscopy off on the lab sheet so to speak, as though it was a complete blood count. The gastroenterologist meets the patients for the first time when an intravenous catheter has already been placed. The patients then sign an informed consent form after they have already drunk the prep or they have had sat on the john for 2 days straight. That is coercion because those patients know they have already done all this. They are not going to refuse because they have already done everything. Often they don’t even read the consent. I don’t practice that because that is how lawsuits can happen. My practice is that I must actually see every patient beforehand, and not 5 min before the procedure but at least a week beforehand. The procedure is explained to the patient regarding the indications, the risks and alternatives, and I document these as well as the fact that I answered all their questions. An exception is emergency procedures obviously. They get a copy of the consent form and they can take it home and read it over 25 times if they want, call up and ask questions about it. Therefore, if we are going to provide informed consent to the patients minutes before we start TPN or before we fill out the TPN order form or before we put the nasogastric tube in, that is not an appropriate informed consent anyway; it is really a kind of coercion when you wave a nasogastric tube in front of them. This is actually a very complicated issue, I am not sure what the right answer is as I have some of my own opinions, but I don’t know if they are correct.

Dr. Morley: First I have a comment and then a question. The comment again is the durable power of attorney of living wills. As a geriatrician I actually deal with these far more often than most people, I have most probably read 1,000 plus of them and I have never been able to interpret at the end what I am supposed to do because they are written by lawyers who say but if, and there is always an if and a whatever. They are totally unintelligible documents when you read them carefully; they are virtually never provided by the patient after discussion with a physician or any health care provider; they are done by people who have no concept. So you will see many people say, I really want somebody to push on my chest if my heart stops but I don’t want ventilation. Certainly with nutrition it is: ‘do you ever want a feeding tube’, ‘yes though not if I have a stroke’. So I really think there are two documents created by lawyers and ethicists which like everything done in my opinion by lawyers and ethicists is most probably to the detriment of the patient. That is a sweeping statement that I don’t totally believe, but nevertheless it is done by those two groups of people with their inability to come to grips with what you really should do. What I do with most of my patients is ask them early on basically what they want. We go through and have this discussion which takes up to an hour, which is why not every patient always get it, and I try to do this long before the patient gets into hospital. At that stage I at least have a baseline of where they want to go, and I send them home to discuss it with their family and ask them to come back and tell me what their family feels about it. If you don’t do that I think we are not talking informed consent, we are making it up from their own. So I think we have got huge problems, and quite honestly I would trust an Italian physician who makes the decision without asking the patient more
than I trust the American legal system, but that is another way of looking at. But more important are the patients who decide not to have nutritional support. So they then become ill, go into hospital and the first thing that happens is they get intravenous fluid, and quite honestly I don’t believe that dying from starvation, having watched many patients do this, is a nice thing. They die with multiple complications and I don’t think they do very well. I think dying from dehydration is a wonderful way to die. I cannot understand why basically in every major hospital in the US the first thing that is done when somebody comes in with withdrawal of nutritional support is to give them an intravenous, to give them fluids, and I would like your comments on the fluid part of it.

Dr. Buchman: To comment on the first part of your statement, I completely agree with you. I think in theory the living wills are wonderful documents but the problem is that again a lot of lawyers try to usurp the authority from physicians. Although there are some that I have dealt with that are plainly written and very easy to follow, I think it is something that needs to be worked on. I think the idea, the concept is good, but it needs to be amended. In terms of the issue of starvation, I didn’t really mention it in my talk but there have been studies done that have looked at discomfort during starvation [2]. We think that it is a terrible thing to die of starvation, it is painful and we should be providing comfort care. But there is actually evidence that would suggest that in starvation endorphin levels are increased in the blood and the body actually sort of takes care of itself, and that ketone production occurs in starvation because it is also associated with a decrease in pain sensation. Surveys have been done in nursing home patients who have been starved [2–4]. Only a very small minority has complained of hunger-like symptoms and they don’t have thirst either, they don’t complain of thirst symptoms. This is contrary to what makes common sense, but unfortunately in medicine there are some things that make common sense that actually aren’t true and there are some things that make no sense at all that are actually true. This unfortunately happens to be the case, at least on the evidence-based data that exist in the literature. On the other hand mouth care is very important. Putting Vaseline® ointment to keep the mouth moist, allowing them some drops of water, ice cubes for example, that actually is very important. Again you have much more clinical experience than I, I am unbiased because I am just simply reading the evidence-based literature and I have not been biased by the clinical experience because by the time a patient just requires any Vaseline and a couple of ice cubes in the mouth in the nursing home I am long gone from their care. Perhaps if your experience is different, then you should convene another study. There are currently several present in the literature.

Dr. Morley: Can I just follow up on that because the studies in the literature are absolutely horrendously badly done. They die of their hunger; no one says that in dying from starvation hunger is the problem. The problem in my patients who die in the nursing home or die in home care if I withdraw nutritional support is that it takes them sometimes 4–6 months because they are usually eating a little bit, they are drinking a little bit, they may have 8–10 hospital admissions. They will certainly finish up with a pressure also somewhere along the line that we could argue whether that was due to the nutritional support or to the lack of it. They will end up with a variety of skin tests, a variety of other things that will create problems. That is never taken into account by someone who goes in and asks if the people are hungry. Well I don’t care whether people are hungry, if they are happy not being hungry, it doesn’t matter to me or even being hungry, but certainly when I watch what happens to my patients when they starve, they don’t die quickly, and that is why I really believe in dehydration. Dehydration, nobody goes longer than a week if you stop giving them fluids and most go in less than that and they go very quickly. In many of the cases where people
have gone in and done these studies, they don’t distinguish between people who are truly dehydrated, who have no response at all. Many of these hunger studies are done in mental patients, and quite honestly I have no idea how to ask mental patients whether they are hungry or not. But again the studies you are talking about were done purely by ethicists, most of whom I know very well and they have never worked in a nursing home. It is amazing how people who never worked in a place can come up with great answers; when they work there they seem to change their mind.

_Dr. Buchman:_ I think you have some excellent points here. One of the things though in terms of the efficacy that you alluded to is there is a new cubism. There is cubism in art but there is also cubism in nutritional support. That would be in contrast to the American court system for example where one is innocent until proven guilty. In Cuba in the court system one is guilty until proven innocent. That is how I view nutritional support. It doesn’t work until it is proven to work, and it has not been proven to decrease pressure sores or otherwise improve survival in nursing home patients. In fact, as pointed out by the study that was presented yesterday, survival and morbidity are decreased in nursing home patients in relation to their age, their underlying diagnosis and their code status, whether they are ‘do not resuscitate’. Those are the only three things that actually have importance in terms of survival and perhaps in the well-being of these patients. Perhaps in the future we will find that there are some other things and perhaps nutrition does play a role, but unfortunately at the present time nutrition just doesn’t have it and we just don’t get it. That is what is in the literature.

_Dr. Bozzetti:_ Just a short comment because Dr. Morley mentioned the Italian physician. I think that informed consent is very important, but if the patient does not want to be informed I will respect his desire.

_Dr. Buchman:_ I would agree, that is part of patient autonomy. If the patient says ‘tell my family that I have got metastatic liver cancer, don’t tell me’, or ‘if it is really bad, don’t tell me’, and they truly believe this, do you have to respect all their decisions? If they have the capacity to understand what you are saying, one has to respect their judgment as well.

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