Enteral nutrition is the act of receiving nutrients through the gut, either orally or through an enteral access device. It has long been used in the hospital and nursing home setting. The number of patients receiving home enteral nutrition (HEN) in the United States has progressively increased, yet the absolute numbers remain difficult to determine.

The use of enteral nutrition has a long history. In 1790, Hunter was first reported to use a mixture of jellies, milk, eggs, sugar and wine through a whale bone covered with eel skin attached to a bladder pump [1]. Einhorn [2] in 1910 provided medical practitioners with guidelines for gastric and intestinal enteral feedings. In the 1950s, attention was placed on the development of enteral formulas. Pareira et al. [3] and Meade Johnson (Evansville, Ind., USA) developed an early enteral formula consisting of milk, milk solids, calcium caseinate, dextrose, maltodextrose, vitamins and minerals. At the same time at Henry Ford Hospital, Barron et al. [4] reported on the use of tube feedings made in the kitchen by blenderizing and straining table food. In the late 1950s and early 1960s a large study on the use of an elemental-based diet was conducted by the Vivonex Corporation (Mountain View, Calif., USA) and the National Institutes of Health. These diets were shown to provide adequate nutrition and maintain a patient’s well-being [5]. The last 3 decades have shown an explosion in the enteral formula industry with the development of many enteral products, some disease-specific. This has provided some specificity in a clinician’s ability to use enteral nutrition as a disease-specific tool, but has complicated the home care industry by the sheer volume of enteral formula choices available to patients and their providers.

HEN has become a growing segment of the total home care arena in the United States. In 1992 it was estimated that there were approximately 73,000 HEN patients with an average yearly expenditure of USD 136 million [6]. Today’s expenditure estimates are very difficult to obtain, not only from the
Medicare population, but also for the Medicaid and private insurer populations. The general consensus is that the HEN population continues to grow at a rapid rate both in numbers and in dollars spent.

There are many common patient disease groups that make up the majority of the HEN population including patients with neurological dysfunction, upper gastrointestinal cancers, anorexia and failure to thrive. These patients, in general, have difficulty with transfer of food from the oral cavity to the stomach. A review of the available data from 1987 to 1991 gives an excellent sample of the types of patients who were sent home on enteral nutrition [7] (table 1).

In the late 1980s and early 1990s, a review of the outcomes of these HEN patients noted that at 1 year between 45 and 60% had died. The overall actual number of patients who are able to go back to oral nutrition ranged between 19 and 30%. In the neurologic-based disease patient group at 1 year, approximately 25% of the patients continued on HEN. The percentage of patients with cancer continuing on HEN therapy at the end of 1 year was much less.

Further review of the Medicare HEN patient population data noted that neuromuscular-based disease patients had approximately 1.2 complications/year, with the majority of these complications related to their primary disease. Those patients with cancer had approximately 3.1 complications/year, again the majority of these were related to their overall primary cancer process. This helped establish the safety of HEN.

More recent data have been collected by Coram Healthcare, Denver, Colo., USA. 17,014 patients were cared for between 1998 and 2002. The mean age was 46.6 years. Thirty-six percent of the patients were more than 65 years of age and 28% of patients were less than 16 years of age. Fifty-four percent of patients were male and 44% were female. The top 5 diagnostic ICD-9 codes were: gastrointestinal dysfunction; protein calorie malnutrition; metabolic or developmental symptoms; intestinal malabsorption, and diseases of the esophagus. The average length of therapy was 357 days. Nineteen percent of patients were receiving concurrent antibiotic therapy and 3% concurrent pain management. The suspected feeding tube infection rate was 5.7% and feeding tube occlusion rate was 6.5%. Rehospitalizations occurred in 9.5% of patients within 30 days of hospital discharge, although the vast

<table>
<thead>
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<th>Table 1. Common home enteral nutrition diagnoses</th>
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<tr>
<td>Neoplasm</td>
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<tr>
<td>Swallowing disorders</td>
</tr>
<tr>
<td>Motility disorders</td>
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<tr>
<td>Crohn's disease</td>
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<tr>
<td>Congenital bowel defects</td>
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<td>AIDS</td>
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majority of these admissions were for the patient's primary disease process, not the HEN.

The quality of life of the HEN patient can be difficult to obtain, often because this patient population can be very difficult to assess. A study of 83 HEN patients used a rough quality of life tool [8]. The patients were assessed at initiation of their HEN and at 1 year, documenting if the patient was better, the same, or worse than they were before starting HEN. Approximately 30% of the original population was available for re-assessment at 1 year, the remaining HEN patients having died. At 1 year, 40% of these patients felt they were better, 40% had no change, and 10% felt worse.

Another study examined 38 adult HEN patients who had been on therapy for 25 months. Most of them had neurologic disease, head and neck cancers or a decreased level of consciousness [9]. Quality of life was measured using the SF-36. Also, the European Quality of Life scoring system and an EQID visual analog scale were used to determine quality of life in these same patients. If the patients could not answer questions because of a decreased level of consciousness, the family was used to measure a subjective quality of life. Some of the patients were completely independent for all their HEN needs, while others had someone at home caring for and helping them. A number of patients had more than 1 person who was participating in their care at home. These HEN patients spent approximately 1.9% of their time in the hospital, or approximately two of every 100 days of therapy. Of those hospital days, 50% were based on a HEN complication, and 50% were based on the patient's overall primary disease process. Quality of life scores measured in these HEN patients were low as compared to a normal control group, most likely because of the significant medical disabilities in the patients receiving HEN. When the quality of life tools were applied to the families of HEN patients who could not respond to quality of life questions, the majority of the families thought the patients were better on therapy than at initiation of therapy. Interestingly, patient quality of life was significantly improved if the patient's age was less than 45 years and if they had one or more caregivers available at home to assist with the HEN therapy.

Additional outcome studies of HEN patients are small in number. The main questions are: does HEN result in a beneficial outcome for patients, and what are the therapy-associated complications? Globally, 18–44% of adults on HEN are ultimately able to gain weight [10]. Only 14% of older adults achieve partial or complete rehabilitation from their primary medical problem compared to 55% of younger patients [10]. The goal of transitioning adults to full or partial oral nutrition occurs in 10–30% of patients [10]. A study by Wilcock et al. [11] focused on HEN complications in 19 patients over 1 year, a very small number. Enteral stomal infections frequently resulted in a visit to the physician or the healthcare worker. The same was true for the onset of diarrhea. Flatulence, although a common complaint, rarely resulted in a physician visit. They reported 14 incidents where patients couldn't obtain their tube feeding
from their home provider: 2 cases due to equipment failure, and 10 cases due
to obstruction of the feeding tube. Only one of those problems resulted in a
visit to a healthcare provider.

Schattner et al. [12] reported on HEN use in patients with dysphagia. This
was a retrospective review over the course of 8 years. The patient’s nutrition
therapy was followed by a nutrition support team, who also monitored their
outcomes. There were 82 patients with a mean age of 61 years. Most of them
had head and neck cancer. Most of the patients were at home on gastric feed-
ings, the minority of them were home on small-bowel feedings. Diarrhea
occurred in approximately 20% of the whole group. Tube site stomal infec-
tion or stomal irritation and leakage occurred in 6–7% of the patient group.

A separate study was published on 416 adult patients with multiple
primary diseases and an age of 65 years or older [13]. Their mean home
enteral feeding duration was 242 days. The 1-month, 1-year, and 5-year
mortality was monitored. Death was associated with the patient’s primary
disease such as dementia, neurologic disease, head and neck cancer, AIDS, or
an age of >70 years. At 1 year, 55% of the patients had died. At 5 years of
HEN, 75% of the patients had died. The overall long-term survival of patients
on HEN demonstrated a rapidly diminishing group with the passage of time.
Only 13% of the patients were transitioned back to oral nutrition. This under-
scores the fact that the likelihood of getting someone off tube feeding once
they’re sent home, is quite low.

Another study focused on 14 patients with cystic fibrosis who put their
own nasogastric (NG) tube in each evening [14]. They received approxi-
mately 1,200 cal/day and were followed for 14.5 months. This high-risk group
of patients was able to gain weight. Their lung function also improved as their
nutritional status improved. Sixty-four percent of this group developed
problems with hyperglycemia. The other major complication was nasal
pharyngitis, a complication that would be expected from nightly placement of
an NG tube.

In a preoperative head and neck cancer study, preoperative enteral nutri-
tion support was given to a group of patients with weight loss [15]. Forty-six
patients received an NG tube and 43 patients received a percutaneous endo-
scopic gastrostomy (PEG). All received HEN training at home. Their pre-
treatment weight loss was approximately 12%. On follow-up, there were no
significant HEN complications. The NG tube-fed patients only had a 15%
compliance rate with NG feedings. Those who were fed with a PEG had a
68% compliance with their home tube feeding regime. Because of nutrition
compliance issues, the PEG-fed patients had a 30% reduction in their post-
operative hospital stay as compared to the NG-fed patients.

In a separate study, 39 patients with head and neck cancer had a PEG
placed in the hospital for nutritional support [16]. Ten patients died before
they left the hospital. The overall median survival was 176 days. An examina-
tion of hospital readmissions after discharge revealed that approximately one
third of the patients had no readmission, one third had 1 hospital readmission and another third came back for 2 or more hospital readmissions, generally related to their head and neck cancer, occasionally related to their nutritional difficulties.

Outcome studies for HEN in the pediatric population exist, although they are few in number (table 2) [14, 17]. In a quality of life evaluation of HEN in children, a questionnaire was administered to 70 families of pediatric patients with HEN using an NG tube [18]. These patients received enteral nutrition for 11,000 days. Both the parent and the child were asked how their feeding tube was working and if the tube feeding was well tolerated. One hundred percent of the parents said that all was going well. Fifty percent of the children stated that all was going well with the nasoenteric tube and tube feeding while the other 50% were unsatisfied with the nasoenteric tube and tube feeding. Interestingly, 10 of 70 of the children had a nocturnal cough only when they were tube fed, raising a concern for tube feeding regurgitation and aspiration. The older children in this study were self-conscious about going to school with a nasoenteric tube, thus opting for nighttime NG tube placement and overnight feedings. Sleep disturbance occurred in parents and children on home overnight NG tube feeds. It was recorded that approximately 60% of the parents were up during the night, often not because the child had a problem, but because the parents wanted to avoid complications. The impact of overnight tube feedings may have a significant effect on the quality of life from the perspective of the child and the parent. This always needs to be taken into consideration.

The management of HEN requires decisions that are made early on by clinicians regarding enteral access, enteral formula, route of formula delivery, monitoring, complication management, and appropriateness for therapy. Careful attention must be given to each of these decisions in order to prevent complications and to ensure favorable patient outcomes.

There are a number of enteral access devices available for home enteral feedings [19] (table 3). A low profile gastric device, or skin level device, is more esthetic than a PEG and is used commonly in the pediatric population (fig. 1) However, it requires the use of a specialized access tube to feed the

### Table 2. Outcome studies in pediatric HEN patients

<table>
<thead>
<tr>
<th>Study</th>
<th>Patient populations</th>
<th>Outcome</th>
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<tbody>
<tr>
<td>Kang et al. [19], 1998</td>
<td>Low normal weight, Malnourished, Stunted</td>
<td>No weight change, Weight gain</td>
</tr>
<tr>
<td>Steinkampf et al. [16], 1994</td>
<td>Cystic fibrosis</td>
<td>Weight gain, Improved lung function</td>
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</table>
patient. Many of the replacement gastrostomy and jejunostomy tubes are balloon-type devices, similar to a Foley catheter, easily replaced at the bedside in the home (fig. 2). However, they have their own related problems including balloon deflation and tube dislodgement. A thorough knowledge of enteral access devices is imperative to be able to understand the problems encountered by HEN patients.
The choice of enteral formula is very patient-specific [20]. The clinician may choose either blenderized, standard, fiber-supplemented, elemental or a specialty formulation. Decisions regarding the appropriate use of a high-nitrogen or a high-calorie formula are often determined by a patient's protein, calorie and volume needs. Electrolyte, mineral and water content also varies between formulas. A clear understanding of the various enteral formula available and their specific contents will allow the clinician to choose the most cost-effective and safest formula.

Delivery methods for HEN are another critical decision for the clinician. This decision would include whether to use bolus feedings, gravity feedings or pump feedings. The range of home enteral pumps varies tremendously (table 4). Each modality has its advantages and disadvantages for the patient, including time commitment, portability, expense and prevention of problems such as aspiration and diarrhea. In general, mobile patients are usually bolus fed and bed bound, or immobile patients are often fed with the use of a pump. These decisions are often based on lifestyle decisions by both the patient and their caregiver.

Monitoring guidelines for HEN patients remain poorly described. Long-term monitoring is required in patients alive at 1 year, approximately 30–35% of patients who originally were started on HEN therapy. These patients generally have significant comorbid diseases. We should be concerned about the patient's weight fluctuations over time. Daily fluid intake and output, and calorie and protein intake are also important. Laboratory analyses that should

Fig. 2. Balloon gastrostomy replacement tube.
be considered include albumin, serum electrolytes, glucose, magnesium, phosphorous, calcium, blood urea nitrogen and creatinine. Vitamin or mineral deficiency is rare unless the patient has other significant comorbid disease processes contributing to these deficiencies. Tolerance to enteral tube feedings should be documented. This includes problems with diarrhea, nausea and vomiting, abdominal bloating and cramping. Although more than 70% of the complications discussed here can be resolved in the home, 25% require visits to or by the physician and an additional 5% hospital admission [21, 22].

Other problems related to HEN use in the United States are secondary to its classification as durable medical equipment by Medicare. Enteral nutrition components fall into the same category as wheelchairs or walkers. Often the enteral formulas, enteral delivery bags and enteral tubing are sent to the patient’s home; this being the only contact between the patient and the home care provider. Nursing is only involved if the patient requires other skilled nursing services. This may lead to some difficulties in attempting to manage and monitor complications of HEN patients.

From the clinician’s viewpoint, monitoring HEN is not a reimbursable activity in the United States. In addition, reviewing and signing the required insurance documentation for HEN is also a non-reimbursed activity. The care of HEN patients can be very labor intensive. Many physicians view

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Table 4. Home enteral pumps

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<thead>
<tr>
<th></th>
<th>Flow rates cm³/h</th>
<th>Battery life, h</th>
<th>Special feature</th>
</tr>
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<tbody>
<tr>
<td>Kendall (Mansfield, Mass.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kangaroo 22</td>
<td>5–295</td>
<td>3</td>
<td>Cigarette lighter adapter</td>
</tr>
<tr>
<td>Kangaroo 224/324</td>
<td>5–300</td>
<td>24</td>
<td></td>
</tr>
<tr>
<td>Kangaroo Entriflush</td>
<td>1–300</td>
<td>8</td>
<td>Automatic flush</td>
</tr>
<tr>
<td>Kangaroo Pet 2100</td>
<td>1–400</td>
<td>14</td>
<td>Ambulatory</td>
</tr>
<tr>
<td>Ross (Columbus, Ohio)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flexiflo III</td>
<td>1–300</td>
<td>8</td>
<td>Ambulatory</td>
</tr>
<tr>
<td>Flexiflo Companion</td>
<td>5–300</td>
<td>8</td>
<td>Automatic water infusion</td>
</tr>
<tr>
<td>Flexiflo Quantam</td>
<td>1–300</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Flexiflo Pet Patrol</td>
<td>1–300</td>
<td>3</td>
<td>Pediatrics</td>
</tr>
<tr>
<td>Zevex (Salt Lake City, Utah)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enteralite</td>
<td>1–600</td>
<td>24</td>
<td>Ambulatory</td>
</tr>
<tr>
<td>EZ Enteral Pump</td>
<td>1–295</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>IVAC (San Diego, Calif.)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Keofeed II</td>
<td>1–300</td>
<td>8</td>
<td>Quick recharge</td>
</tr>
<tr>
<td>Abbott (Chicago, Ill.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breeze Lifecare 175</td>
<td>1–999</td>
<td>5</td>
<td>Quick recharge</td>
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<tr>
<td>Elan Pharma (Dublin, Ireland)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>KM60,70,80,85</td>
<td>5–2,000</td>
<td>6.5</td>
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HEN as not routinely requiring monitoring, compared to home parenteral nutrition patients. Although this may occasionally be true, most long-term HEN patients are debilitated and require routine clinical monitoring. Also, many clinicians may be uncomfortable with treating the complications of HEN because they are not familiar with enteral access devices or enteral formulations.

In conclusion, the HEN population is a growing. Substantial nutritional benefit has been documented in appropriate patient populations. The HEN outcome data are very often consistent with the patient’s primary disease process. Nutrition is not a cure for their primary disease process. Reported complication rates vary tremendously. A standardized approach to reporting complications of HEN patients needs to be developed.

Long-term HEN patients do exist, although they are in the minority of the patients started on enteral nutrition in the hospital. HEN patient monitoring is often not perceived to be as important as with home parenteral nutrition patients. The HEN patient population is a high-risk group that often requires careful monitoring. There are multiple medical decisions to be made by the clinician prescribing HEN. These decisions often have a tremendous impact on the patient's outcome. Only with adequate oversight and rigorous patient policies and procedures can satisfactory HEN outcomes be obtained.

References

Discussion

Dr. Buchman: One of the things that I will touch on briefly in my talk tomorrow is something that I just recently found out and perhaps you could comment on. In nursing homes, especially where a lot of patients receive enteral nutrition, generally via percutaneous endoscopic gastrostomy (PEG), reimbursement is substantially greater for those patients receiving enteral feeding via a PEG than those receiving the same enteral feeding via a nasogastric (NG) tube. In both cases reimbursement is substantially greater than for those patients who don't receive any enteral nutrition for whom staff must be hired to actually feed them. So do you think the fact that nursing homes make a lot of money out of enteral nutrition drives the significant increase in the number of enterally fed patients in the nursing homes and the numbers that you stated on the doubling of patients in the US on enteral nutrition? Does that actually largely reflect the increased volume from the nursing home?

Dr. DeLegge: The whole market does it. I think the whole market has a lot to do with consumers because many people are asking for things. Families ask for it because they have heard of it from other people, and also the fact that physicians by and large are a little more knowledgeable about what they have available. But I agree with you, the nursing home situation in the US is a mess, and it is kind of a square box that is meant to keep you in and not able to get out. If I send someone to a nursing home with an NG tube, compared to a PEG, the nursing home gets less reimbursement for enteral nutrition. If I send someone to a nursing home with oral feeding, meaning that they are going to be fed my mouth, this means that someone has to warm up their food, someone has to sit at the bedside, place the food in their mouth, watch them swallow and thus give them some sort of bedside feeding. In fact because of the time constraints, often those patients by and large ultimately won't be fed adequately. So there is a real drive from the nursing homes in the US to put in PEG tubes as often as possible in anybody with any dysphagia simply because they don't have the resources to do what they would need to do otherwise. The Federal Government, and the Commissions of Accreditation for nursing homes inspect them and will give major negative points for nursing homes with patients who are losing weight. So although the patient may be losing weight appropriately, meaning that they have end-stage
dementia and are in their last 2 months of life, the nursing home would be criticized because the patient was allowed to lose weight.

Dr. Lochs: Did your data include liquid oral supplements? If one looks at the literature it seems that oral supplements are even more effective than tube feeding which might be due to the argument that in the earliest stage there is still some reversal of malnutrition possible or something like that.

Dr. DeLegge: Unfortunately the database that I have does not include those patients who went home on oral supplements. My own preliminary data from Charleston justify what I was just trying to say earlier today. If I have a patient with a reversible process, meaning perhaps that they have had pancreatic surgery for cancer and are going to go home but are not consuming enough calories, the utilization of an oral supplement seems to be very beneficial. When I have elderly patients who have started to stop eating, I have not had good success with providing oral supplements to that population because it doesn't change what they have actually taken in. They use the supplements as a meal substitute.

Dr. Bowling: Forgive me if I misunderstood this. But did you say that 16% of these patients require parenteral feeding as well? So 1 in 6 of your patients are on two methods of nutritional support?

Dr. DeLegge: No, that is not correct. What happens is 1 in 6 are going from enteral to parenteral and back to enteral, based on the physician's decision for whatever reason that is. This is a relatively high amount.

Dr. Elia: I was interested to hear about the readmission rates of 10–15% in the US, which are in excess of what we see in the UK and probably other European countries. This raises the question as to whether the patients are appropriately trained before they go home, and whether there are appropriate plans in place to ensure continuity of care. Do you think there is a lack of an appropriate policy, and if so what are the reasons behind this?

Dr. DeLegge: It is a secondary defect. The amount of education that is done prior to discharge is very minimal, the amount of actual clinical intervention at home by a clinician, once the patients are discharged, is again pretty minimal. You are absolutely correct, this is an area where we need to have standardized protocols for intervention. We do have some standardized protocols at our own center. But I can assure you that this is a rarity for what happens in the US, so we are sorely lacking in patient follow-up.

Dr. Labadarios: Do you give enteral nutrition as a means of sustenance just to survive, or do you give disease specific enteral nutrition, for example in dementia? If you do it from the point of view of altering the course of disease, whatever that may be, do you have any data on that aspect of your presentation?

Dr. DeLegge: Within which group, the dementia patients?

Dr. Labadarios: Any group in terms of complications, and in terms of outcomes.

Dr. DeLegge: The few studies that I showed you in which the complications were very low in number included head and neck cancer, pharyngeal cancer, and cystic fibrosis; definitively good data and outcomes.

Dr. Bozzetti: I would like to come back to the patients with the incurable disease on enteral nutrition. Why don't you accept that the final survival rate is an indicator of outcome? If you consider that healthy people undergoing total macronutrient starvation would survive only 2 or 3 months, it is obvious that if there is a group of patients who survive more than 3 months, this can be possible only thanks to the parenteral or enteral support.

Dr. DeLegge: I agree with you. I was questioned a month ago by a major health insurer in the United States as to why I wanted to place a feeding tube in a patient with terminal cancer. This patient was still functional and able to walk, so I wanted to
provide him with home enteral nutrition (HEN). I was told that HEN wasn’t going to change his outcome. So the patient went home anyway on HEN but had to pay for it out of his own pocket. But you are absolutely correct that there are good data showing that the terminally ill who are still functional can in fact benefit from nutritional support.

**Dr. Hébuterne:** You mentioned quality of life as an important issue in HEN patients, but we have two major problems in assessing quality of life. We have no specific tool and many patients are incompetent, patients with neurological disease are incompetent, are not able to understand. I would be happy to have your opinion on this point, how to assess quality of life in these patients.

**Dr. DeLegge:** I readily admit that our ability to assess quality of life in those patients is poor. There is a very good recent scoring system looking at pain in patients with dementia [1]. Additionally it measures some quality of life issues, and it has been standardized. However, I would agree with you, most of what we do is talking and asking the family if the patient is doing better?

**Dr. Hébuterne:** I think it is really important to have the patient’s opinion. For example in my center if we ask a doctor about the incidence of diarrhea and constipation in HEN patients it is between 15 and 20%, but if you ask the patients 60% of them are not happy because they have constipation and 40% of them have diarrhea, nobody is happy. So the patient’s opinion is probably different from that of the caregiver.

**Dr. DeLegge:** I agree.

**Dr. Morley:** I don’t think it is fair to blame the nursing homes for the high amount of tube feedings in the United States. In the United States we have a medical legal system that rules by its own laws that virtually force you to have tubes put into people if the family wants it. So the number one thing is that the family has to be asked and really the reason is the family more than anything else. The second reason, if you want to say it has anything to do with money, is gastroenterologists who have no problem whatsoever in putting tubes into people who I think are dead. But they put them in and sent the patient back to me in the nursing home. The third problem is so to speak the therapist who has learned that any dysphagia requires altered food. We all aspirate a little bit but in a nursing home everybody aspirates and therefore not everybody should be fed. And if you go down that road you go very rapidly to having no choice but to put in a tube. I don’t think that I have ever seen a nursing home administrator come to me and say we will make more money if you put in a tube than if we feed people; I have never had that pressure, but I have certainly had other pressure. So I think we need to be very careful not to blame the nursing homes. The second part of it, which I think is also important, is you said you had a 15% readmission rate. I presume that is for everything, not just tube-related. That is where the difference to England is, we put tubes into people who would never ever get a tube anywhere else in the world. I mean these people wouldn’t be discharged either, we discharge people after 4–5 days and we send them home tremendously sick and that 15% admission rate for this population is low. For our subacute care we run a 30% readmission rate because of the type of people we are discharging. So I think again we should not blame the tube for a 15% readmission rate.

**Dr. Buchman:** I would like to address Dr. Morley’s comment. Being a gastroenterologist I can tell you there are people in my medical center that would put tubes in people who are nearly brain dead because reimbursement is significant for PEG placement. However, it doesn’t take away from the fact that the nursing homes do make a lot of money from patients who are fed via a PEG and they drive this industry. Nurses also often refuse to accept a patient from the hospital without a PEG I suspect often because of reimbursement issues. If patients are in an acute care hospital in the US,
they can’t stay there, they have got to go somewhere. In fact there is a survey of 42 states in which all 42 state that the reimbursement was significantly greater for having the PEG tube [2]. In fact in the US it almost seems by law that we must spend 90% of our health care dollars in the last 30 days of life. It contrasts significantly to Europe because many of the patients who get tubes in the US never would have even been admitted to hospital in Europe. But we are forced to take care of these patients, not so much because of the family but because of where they ultimately go. Our physicians can convince the family of anything depending on how they bias or slant the facts.

Dr. Correia: I would like to go back to the advanced cancer patients, the terminally ill patients as Dr. Bozzetti mentioned. I think we cannot measure outcomes in terms of survival or quality of life because as we have seen it is very complicated to define quality of life, etc. But we do have a very good argument and it comes from hunger strikers; as we have seen in several natural trials if they don’t eat they die after 6 weeks [3]. So if we don’t feed these patients I cannot show insurance companies or any other person that they would do better, but they certainly would not die of passive euthanasia. From what I know in most of our countries euthanasia is not allowed or in terms of law it is not accepted. So the justification to these insurance companies is just that if you don’t allow enteral nutrition you are pro-euthanasia, which again is not legal.

Dr. DeLegge: I will try that next time.

Dr. Schwab: I would like to come to this extraordinary mortality rate after PEG placement which to me is actually a disaster. You have to imagine a procedure is indicated in patients and you think you can supply nutrition for at least 1 month, but a fifth of them is dead after this time.

Dr. DeLegge: They are not dying from the tube, they are dying from their primary disease.

Dr. Schwab: The problem is that these are probably very valid data because I recall 4 articles [4–7] in which exactly the same 20% is stated, not only in your country but in ours also. So the question is what are we doing wrong? Is our selection probably wrong? I recall just one idea that inpatients are doing much worse than outpatients. There was a study from New York [4] showing this quite nicely. But I am not aware of any other risk factors for early mortality because we have to exclude these patients because it is, as everybody would probably agree, just nonsense to put a tube in these patients.

Dr. DeLegge: Currently we have a prospective study going on in our hospital using something called the Charlson co-morbidity index, which basically is going to score patients for severity of disease prior to them getting a feeding tube. We will look for an association between that index and patient outcome to see if perhaps that can help better chose patients who should or should not get a tube. In the US generally what happens is that the family doctor and the family have already decided that they want a feeding tube. The specialists, either the surgeon or the gastroenterologist, is consulted to place the feeding tube. If the specialist decides a tube is not warranted, it can be very difficult to convince the patient and/or their families who have already made up their minds. So part of the issue in the US is education, not so much at the specialist level, but at the primary care level.

Dr. Powell-Tuck: The proportion of patients fed for cancers has dropped over the last 20 years or so. I think it was something like 55% and went down to 20%. Is this just a trick of proportions or is it a reduction in numbers?

Dr. DeLegge: That is a great question. The data I did not show you were with regard to patients receiving home parenteral nutrition. There has been some shifting of patients getting home enteral to the home parenteral side, and there has also been
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some drop off of people who were previously getting tube feeding for obviously terminal disease. The other issue is the fact that the neurologic group as a whole has just exploded in numbers, which makes the cancer population by and large look smaller too.

References