Nutritional Support in Neurological Diseases

Module 25.2

Indications and Ethical Aspects of Nutritional Support in Neurological Diseases

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Learning Objectives

- Know the importance of individualized nutritional assessment in patients with neurological disease in order to address the different nutritional problems;
- Know the most appropriate use of nutritional support in neurological patients;
- Understand the clinical challenge of establishing and maintaining placement of tube feeding in neurological patients;
- Know the indications for gastrostomy in neurological patients;
- Know the ethical, legal, and moral implications of nutritional support in patients with progressive dementia.

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   4.1 Tube feeding
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Key Messages

- Patients with neurological diseases are frequently at risk of malnutrition due to eating difficulties and weight loss;
- Nutritional intervention is indicated in neurological patients with malnutrition or nutritional risk;
- In geriatric patients with severe neurological dysphagia, enteral nutrition is recommended to ensure energy and nutrient supply and to maintain or improve nutritional status;
- There is no do data available to support tube feeding versus oral feeding in advanced dementia to prevent aspiration pneumonia, reduce the risk of pressure sores or infections, improve function, or prolong survival;
- In geriatric patients with severe neurological dysphagia, requiring long-term nutritional support a PEG is preferred to a naso-gastro tube as PEGs are associated with less treatment failures, and achievement of better nutritional status;
Patients with advanced dementia are not usually considered appropriate candidates for artificial feeding via PEG tubes; Legally and ethically, specialized nutritional support should be considered a medical therapy; The debate whether or not to give nutritional support in different neurological situations would be avoided if every patient made an unambiguous living will outlining advance directives.

1. Introduction

Patients with neurological disease frequently develop malnutrition. Although some of these patients develop overweight or obesity, malnutrition is more frequently observed with both macro- and micronutrient deficiencies. Acute brain injury and stroke are followed by immediate nutritional and metabolic changes. In severe progressive degenerative disorders, nutritional risk is usual due to eating difficulties and weight loss. The prevalence of malnutrition in neurological patients has been obtained, in general, from studies of mixed groups of patients. However, Kennedy et al, in a survey performed in patients with psychiatric and neurological diseases found that >60% had a BMI <20 kg/m² (1). Dysphagia and progressive dysfunction are the most frequent causes of impaired oral feeding in neurological diseases. It is important not only to diagnose the different stages of dysphagia but also to prescribe the most appropriate nutritional support for these clinical situations (for more information see Module 25.1). Progressive dysfunction leads to decline in the ability to care for oneself, and the ability to obtain, prepare and present food to the mouth. Both, dysphagia and progressive dysfunction increase the risk of aspiration.

We must accept that nutritional support should be considered a valuable adjunctive therapy in neurological patients with malnutrition or risk of malnutrition.

2. Indications of Nutritional Support in Neurological Disease Patients

Early nutritional assessment is mandatory in patients with neurological impairment. Important nutritional information is obtained from the diet history (nutrient intake, pattern of current eating, chewing capacity and the existence or not of swallowing difficulties). Early recognition of dysfunction (decline in function and in the ability to care for oneself) is important as this may herald nutritional decline (Table 1). Recording of unintentional weight loss and a consideration of possible drug-nutrient interactions are part of the nutritional assessment (2) (Table 2).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
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<tbody>
<tr>
<td>Depression</td>
<td>Food rejection</td>
</tr>
<tr>
<td>Decline in ability to care for oneself</td>
<td>Not available to by or prepare food</td>
</tr>
<tr>
<td></td>
<td>Not able to present food to the mouth</td>
</tr>
<tr>
<td>Difficulties in oral process</td>
<td>Food aversion</td>
</tr>
<tr>
<td></td>
<td>Ataxia, apraxia, visual impairment</td>
</tr>
<tr>
<td></td>
<td>Chewing ability impaired</td>
</tr>
<tr>
<td></td>
<td>Swallowing difficulties (liquids or different textures)</td>
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<tr>
<td></td>
<td>Prolonged time needed to eat a meal</td>
</tr>
<tr>
<td>Other</td>
<td>Constipation</td>
</tr>
<tr>
<td></td>
<td>Drugs that can compromise food intake or food absorption</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Drug</th>
<th>Main nutritional implications</th>
</tr>
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<tbody>
<tr>
<td>Amantadine</td>
<td>Anorexia</td>
</tr>
<tr>
<td>Barbiturates</td>
<td>Decrease caloric requirements, and cause constipation</td>
</tr>
<tr>
<td>Cyclosporine</td>
<td>Hyperkalemia, hyperlipidemia, and hypomagnesemia</td>
</tr>
<tr>
<td>Erythromycin</td>
<td>Diarrhoea</td>
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</table>
In patients with Alzheimer’s, altered activity levels, depression, impaired memory and in the terminal stages, dyskinesia and inability to self-feed, contribute to the development of undernutrition. In Amyotrophic Lateral Sclerosis and Myasthenia Gravis the difficulties in chewing and swallowing are important and the patient is often in fear of aspiration during eating. In Multiple Sclerosis, swallowing and coordination difficulties increase as the disease progresses. In Parkinson’s disease not only are sucking and swallowing reflexes reduced but also drooling and tremor, and rigidity may be a problem during eating (3). In Stroke, signs and symptoms depend on the area and extent of brain affected (4). In traumatic brain injury, altered consciousness, vomiting, altered blood pressure, seizures, paralysis, and aphasia, all contribute to the difficulty with oral feeding (5). In this acute situation, due to the relationship between the brain and glucose regulation and the frequent use of steroid treatment, hyperglycaemia may be unavoidable (6).

If malnutrition or nutritional risk is present (for more information see Topic 3), an appropriate nutrition care plan should be early implemented in collaboration with the patient, his/her family and caregivers.

3. Most Appropriate nutritional support in Neurological Patients with Malnutrition Risk

Energy and protein requirements should be estimated for each patient according to the neurological disease present (while those with neurological disorders involving seizures or muscular twitches require a high energy intake, those with spinal cord injury require fewer calories than predicted by traditional stress factors). The patient’s current nutritional status, and pathophysiological condition (respiratory insufficiency, renal failure, pharmacological sedation) should also be taken into account. Indirect calorimetry is the gold standard to evaluate energy needs in traumatic brain injury (7).

Fluid and nutrient intake should be monitored regularly to avoid the development of malnutrition or fluid and electrolyte imbalance.

The goals of nutritional support are to treat established malnutrition and/or to prevent the development of malnutrition in a patient at risk. It is not always easy to increase oral intake sufficiently in neurological patients, even using foods of modified consistency or oral supplements. It may therefore be necessary to use artificial means to provide sufficient nutrients to avoid additional weight loss and dysfunction due to malnutrition.

To decide upon the most prudent and appropriate method of nutritional support in neurological patients it is first necessary to undertake an assessment of oral, swallowing and GI function (Fig 1). Before deciding to administer nutritional support to neurological patients, it is mandatory to discuss the benefits and risks of the various options with the patient, family and other carers.
Nutritional risk or malnutrition

Oral nutrition possible

Dietary counseling

Positive answer

Follow-up

Oral nutritional supplements

Negative answer

Gastrointestinal tract suitable

Enteral nutrition

Follow-up

Gastrointestinal tract no suitable

Parenteral nutrition

Follow-up

Oral nutrition impossible

Figure 1 Nutritional Intervention Algorithm

3.1 Diet Counselling

Neurological patients, who have difficulties with eating or swallowing, are usually unable to consume their recommended daily allowances of both macro- and micronutrients. The first step is counselling concerning methods to overcome chewing and swallowing problems and dietary manipulation eg modified consistency foods and diet fortification. In general, small, frequent meals, and between-meal snacks are better tolerated than large meals. Some times, finger foods, lightweight utensils, unbroken dishes and utensils, and special feeding utensils, can contribute to better food preparation and self-feeding (8). In one report a whole formula diet had a positive impact on nutritional status in Alzheimer’s disease patients (9). Knowing that a diet rich in proteins delays levodopa absorption, it may be helpful to redistribute protein intake throughout the day or to use a low protein diet of high biological value in patients receiving this drug (10). Constipation is also a problem in these patients, and it is therefore important to provide adequate fluid and fibre.

3.2 Dietary Supplements

When energy or protein intake falls to less than 50-75% of requirements, liquid or semi-solid oral supplements should be tried, although this is not always successful (11, 12). It is important that the patient and carers understand that the purpose is not to replace all the diet with these products but to supplement the diet and achieve an adequate total intake (13) (for more information see Module 8.2).

Although Stratton et al (14) reviewed the evidence favouring nutritional support in a number of conditions; they found few studies specifically on neurological patients (15). Further research is needed to establish the effectiveness of counselling and dietary supplements in this group of patients.

3.3 Artificial Nutrition

Those neurological patients with clinical conditions in which oral intake are impossible, inadequate, or unsafe are candidates for artificial nutrition. Enteral tube feeding is preferred to PN in nearly all neurological patients being safer, cheaper, and easier to manage.

Tube feeding can be delivered through different routes and tubes, depending on the patient’s situation and the likely duration of the treatment (Fig. 2)
If the patient has a traumatic brain injury, tube feeding should be initiated early to minimise loss of lean mass and improve immune function; also because it is associated with improved neurological outcome. Sometimes adequate enteral feeding is impossible initially due to gastroparesis or enteral dysfunction. Some patients with brain injury and intracranial oedema may require an initial period of parenteral nutrition until GI function returns.

4. Tube Feeding in Advanced Neurological Disease

Whether to initiate tube feeding is one of the most challenging dilemmas facing families, clinicians, and institutions caring for patients with advanced dementia. Evidence suggests that artificial nutrition support may provide more burden than benefit as it neither prolongs life nor improves its quality. Recent data indicate that tube feeding may be associated with increased risks, e.g. aspiration, and discomfort in these population (16, 17). Tube feeding represents a considerable use of health care resources which is unjustified if it confers no benefit. Furthermore, decisions regarding long-term tube feeding may change with time, because clinical circumstances evolve and individuals change their minds.

4.1 Tube Feeding

In theory, tube feeding can be a nutritional solution for demented patients. However, the reality is completely different and, in several studies, tube feeding did not result in improved nutritional status in demented patients. Factors that contributed to this lack of nutritional effects were diarrhoea, clogging of the tubes, and the frequent tendency of those patients to pull out the tubes. There is no data available to support tube feeding versus oral feeding in advanced dementia or that it is able to prevent aspiration pneumonia, reduce the risk of pressure sores or infections, to improve function, or prolong survival (18).

Although there is an extensive bioethical literature arguing that the use of tube feeding is not mandatory, and despite the opinion by a majority of Medical Societies and Supreme Courts, that artificial nutrition and hydration constitute a form of medical care, family and caregivers continue to plead that they cannot let a relative to die of starvation. This situation requires sensitive and sympathetic handling over a period of time to persuade those concerned that the burden outweighs the benefit.
According to the ESPEN Guidelines on enteral nutrition: geriatrics (19) (Table 3).

Table 3 ESPEN Guidelines on enteral nutrition: geriatrics

<table>
<thead>
<tr>
<th>Clinical situation</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>In geriatric patients with severe neurological dysphagia, enteral nutrition is recommended in order to ensure energy and nutrient supply and, thus, to maintain or improve nutritional status</td>
<td>A</td>
</tr>
<tr>
<td>In demented patients ONS or tube feeding may lead to an improvement of nutritional status</td>
<td>C</td>
</tr>
<tr>
<td>In early and moderate dementia consider ONS and occasionally tube feeding to ensure adequate energy and nutrient supply and to prevent undernutrition</td>
<td>C</td>
</tr>
<tr>
<td>In patients with terminal dementia, tube feeding is not recommended</td>
<td>C</td>
</tr>
<tr>
<td>In geriatric patients with severe neurological dysphagia, enteral nutrition has to be initiated as soon as possible</td>
<td>C</td>
</tr>
<tr>
<td>In geriatric patients with neurological dysphagia, enteral nutrition should accompany intensive swallowing therapy until safe and sufficient oral intake from a normal diet is possible</td>
<td>C</td>
</tr>
</tbody>
</table>

4.2 Gastrostomy Feeding Tubes
Since the first description of endoscopic gastrostomy, the technique has gained acceptance and nowadays percutaneous endoscopic gastrostomy is preferred to a nasogastric tube for provision of long-term enteral nutrition (for more information see Module 8.3).

Theoretically, the use of PEG should improve the quality of life of the patient, decrease the episodes of aspiration, reduce the frequency of pressure ulcers, and promote wound healing. However, several articles have questioned the benefit of PEG tube placement in patients with advanced dementia (20), and also a notable discord exist between physician opinion, and reported practice regarding PEG tubes in advanced dementia patients (21).

A patient with severe neurological dysphagia without other deficits in quality of life, after an acute stroke, is quite different from a patient with advanced dementia or a permanent vegetative states (22, 23).

The ESPEN Guidelines on enteral nutrition: geriatrics (19) state that although a PEG is preferable to a nasogastric tube for the long term feeding of dysphagic neurological patients, tube feeding is not usually appropriate in patients with advanced dementia (24).
4.3 Dietary Recommendations for Oral Feeding in Patients with Severe Dementia

At this stage of the disease, dietary recommendations are to maintain patient comfort and intimate patient care, taking time to ensure that oral intake of food and fluids is maintained, using all the nursing skills available to improve intake and avoid aspiration e.g. posture, food consistency etc.

5. Ethical Issues

Decisions concerning withholding or withdrawing of nutrition support require a consideration of both ethical and legal principles (both at common law and statute including the Human Rights Act 1998). Healthcare professionals involved in starting or stopping nutritional support should obtain consent from the patient if he or she is competent. If the patients is nor competent (neurological patients, were, for the most part, unable to make their own healthcare decisions at the time of tube placement), the consent must be obtained from the caregiver or family member with legal power of attorney. However, if the patient is not competent to give consent, the physician has to act in the patient’s best interest. The effect of tube feeding on the quality of life and functional status of the patient may be the most relevant outcomes to be considered (25, 26).

The debate about administration or not of nutritional support in different neurological situations would be avoided, theoretically, if every patient had an advance directive or living will document (27). Advance directives are written documents which say what a person wants or does not want if he/she, in the future, cannot make his/her wishes known about medical treatment. This document would indicate whether and for how long patients would desire certain treatments or services. If an advance directive is available, this helps to overcome the problems created by family disagreements, cultural and religious differences between caregivers and patients. Unfortunately, most patients do not have a living will, and not all the patients who do have expressed wishes specifically about tube feeding.

In these situations a person with an identified durable power of attorney for health care is legally authorized to make decisions. In the absence of such a person and of any previously expressed wishes by the patient, surrogate decisions can be made, always remembering that the doctor is not obliged to undertake any treatment which he or she does not consider to be in the best interests of the patient. Surrogate/family decision making allows close family members or friends to make treatment decisions for a patient who has not executed an advance directive. Decision-making programs have been developed to help decision makers understand the risks and benefits of care options, and to consider the value of these potential risks and benefits, and actively participate in decision-making. It is important that decision makers receive adequate support from the healthcare team in making their decision. Decision makers should (a) give priority to the previously expressed wishes of the patient, (b) be guided by what they feel the patients would choose if she/he were competent (c) set aside their own distress or irrational feelings of guilt and be guided solely by what they understand to be in the patient’s best interests (28). If there is a disagreement, the local ethical committee should be approached for advice.

It may be of interest to recall the ethical and legal aspects of ASPEN guidelines (29) (Table 4):

<table>
<thead>
<tr>
<th>Situation</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Legally and ethically, specialized nutritional support should be considered a medical therapy</td>
<td>A</td>
</tr>
<tr>
<td>Care providers should be familiar with current evidence of the benefits and burdens of specialized nutritional support</td>
<td>C</td>
</tr>
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</table>

Table 4 Ethical and legal aspects of ASPEN guidelines
Patients should be encouraged to have living wills and/or advance directives and to discuss with their loved ones their wishes in the event of a serious or terminal accident or disease

Adult patients or their legally authorized surrogates have the right to accept or to refuse specialized nutritional support

The benefits and burdens of specialized nutritional support, and the interventions required to deliver it, should be considered before offering this therapy

Institutions should develop clear policies regarding the withdrawal or withholding of specialized nutritional support and communicate these policies to patients in accordance with the Patient Self-Determination Act

6. Summary

Patients with acute brain injury, stroke, or severe progressive degenerative disorders frequently develop malnutrition. Early nutritional assessment is mandatory in neurological patients and nutritional support should be part of the treatment when malnutrition or the risk of developing malnutrition is present. Energy and protein requirements should be estimated for each patient according to their neurological disease and pathophysiological situation. Assessment of the chewing and swallowing process and of gastrointestinal function should be carried out before deciding on the most appropriate method of nutritional support. The first step in nutritional intervention is diet counselling, and dietary manipulation and fortification. If this fails, then oral supplements should be tried. However, not enough studies had been done in neurological patients to establish the effectiveness of counselling and nutritional supplements on a firm basis. Tube feeding should be initiated early in traumatic brain injury and in neurological patients with dysphagia to ensure adequate energy and nutrient intake. In patients with advanced dementia tube feeding is not recommended. While in neurological patients with persistent severe dysphagia but without other deficits in quality of life a PEG is the best option, although this is contraindicated in patients with advanced dementia. The debate concerning administration or not of nutritional support in different neurological situations, would be avoided if every patients had written advance directives. If this document is not available, in some countries, though not in all, a family member may be legally authorized to make decisions. In most countries a previously drawn up legal power of attorney may legally allow the person designated to take decisions on behalf of the incompetent patient.

References

20. A.S.P.E.N. Board of Directors and the clinical guidelines task force. Guidelines for the use of parenteral and enteral nutrition in adult and pediatric patients. JPEN 2002;26, Suppl1:56 SA-605A.