ESPEN Congress Leipzig 2013

The ESPEN Guidelines session

Nutrition support in neurodegenerative diseases

R. Burgos (ES)
ESPEN GUIDELINES ON NUTRITION SUPPORT IN NEURODEGENERATIVE DISORDERS

Dr. Rosa Burgos
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Invited editorial

ESPEN disease-specific guideline framework

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An independent evaluation by experts of specific fields with an interest and experience in medical nutrition is mandatory. Professional and international societies of nutrition are by nature committed to this task, in collaboration with specialty societies when applicable. The willingness of ESPEN as a multi-national society is to increase its leadership in guideline development and dissemination, and to increase the professionalism by promoting a systematic and standard approach of the evidence to be translated for clinical practice. Several sets of guidelines were published under the auspices of ESPEN, from 1997 to 2009, but the methodology used for the development of these guidelines was not fully standardized. Collaborations with specialty societies are desirable, to ensure the largest dissemination among specialists in other fields than nutrition.

The experts nominated for these tasks are all practicing clinicians working in the field of recommendations. They all have an interest in nutritional issues, even though their main activity may often be related to their primary specialty.
Professionals involved in the Guidelines: 
ESPEN disease-specific guideline framework

An independent evaluation by experts of specific fields with an interest and experience in medical nutrition is mandatory. Professional and international societies of nutrition are by nature committed to this task, in collaboration with specialty societies when applicable. The willingness of ESPEN as a multi-national society is to increase its leadership in guideline development and dissemination, and to increase the professionalism by promoting a systematic and standard approach of the evidence to be translated for clinical practice. Several sets of guidelines were published under the auspices of ESPEN, from 1997 to 2009, but the methodology used for the development of these guidelines was not fully standardized. Collaborations with specialty societies are desirable, to ensure the largest dissemination among specialists in other fields than nutrition.
Society involved in the Guideline development

European Society for Swallowing Disorders
ESPEN GUIDELINES ON NUTRITION IN NEURODEGENERATIVE DISORDERS
GUIDELINE DEVELOPMENT GROUP

• **Chairperson:** Rosa Burgos

• **Members of the GDG:**
  
  • Laurence Genton Graf  
  Clinical Nutrition, University Hospital Geneva, Switzerland.

  • Jean Claude Desport  
  Nutrition Unit. ALS Center. University Hospital Limoges, France.

  • Suzanne Yates  
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  • Marjolein A van der Marck  
  Dept Neurology. Radboud University Nijmegen Medical Centre. Netherlands.
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• Adriano Chió
  ALS Center. Dept of Neurosciences. University of Torino. Italy.

• Olle Ekberg
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• Pere Clavé
  Associated Professor of Surgery. Universitat Autónoma de Barcelona. Hospital de Mataró. Barcelona, Spain. Chairman of ESSD.
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• Renee Speyer. SLT
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KEY DISEASES

- Classification of Neurodegenerative Disorders with Nutritional implications (ICD-10 based)

  - **Systemic atrophies primarily affecting the central nervous system** (G10-13)
    - Huntington’s disease
    - Hereditary ataxia
    - Spinal muscular atrophy and related syndromes
      - Motor neuron disease (G 12.2)
        » Amyotrophic lateral sclerosis (ALS)

  - **Extrapyramidal and movement disorders** (G 20-26)
    - Parkinson’s disease
    - Other degenerative diseases of basal ganglia (Progressive supranuclear palsy)

  - **Demyelinating diseases of the central nervous system** (G 35-37)
    - Multiple sclerosis (MS)

WHO | International Classification of Diseases (ICD) (http://www.who.int/classifications/icd/en/)
1. Nutritional support in neuromuscular disorders (with special attention to Amyotrophic Lateral Sclerosis).

2. Nutritional support in extrapyramidal (Parkinson’s Disease) and movement disorders.

3. Nutritional support in demyelinating diseases (with special attention to Multiple Sclerosis)


5. Ethical issues.
ESPEN GUIDELINES ON NUTRITION IN NEURODEGENERATIVE DISORDERS
RELEVANT ISSUES TO BE ADDRESSED IN THE GUIDELINES ON NUTRITION IN NEURODEGENERATIVE DISORDERS

1. Nutritional support in neuromuscular disorders (with special attention to Amyotrophic Lateral Sclerosis).

2. Nutritional support in extrapyramidal (Parkinson’s Disease) and movement disorders.

3. Nutritional support in demyelinating diseases (with special attention to Multiple Sclerosis, MS)

Common issues
Common issues to the 3 main groups of pathologies:

- Prevalence of malnutrition.
- Nutritional status as a prognostic factor for survival.
- Nutritional requirements.
- Prevalence and natural history of oropharyngeal dysphagia.
Common issues to the 3 main groups of pathologies:

- At what stage of the disease do we need to screen for dysphagia?

- Are there specific methods for screening and clinical diagnosis of OD?

- What are the therapeutic effects of behavioral, rheological and rehabilitation treatments for OD in patients?
1. Nutritional support in neuromuscular disorders (with special attention to Amyotrophic Lateral Sclerosis)

Specific issues
Nutritional requirements in MND-ALS patients.
  - Non-ventilated patients
  - Ventilated patients

What is the timing for gastrostomy tube in MND-ALS patients?

Relationship between survival and respiratory function at the time of gastrostomy.

What is the best approach for gastrostomy in MND-ALS patients: percutaneous endoscopic gastrostomy or radiologic gastrostomy?
NUTRITIONAL SUPPORT IN NEUROMUSCULAR DISORDERS  (with special attention to ALS)

- Does enteral nutrition improve quality of life in MND-ALS patients?

- Does enteral nutrition improve survival in MND-ALS patients?

- Is there a role for long term parenteral nutrition (home PN or in rehab facilities) in ALS patients?

- Specific characteristics of OD and Malnutrition in other NM diseases:
  - Myastenia Gravis
  - Muscular dystrophies: Myotonic Dystrophy and Oculopharyngeal Muscular Dystrophy
2. Nutritional support in extrapyramidal (Parkinson’s Disease) and movement disorders.

Specific issues
NUTRITIONAL SUPPORT IN EXTRAPYRAMIDAL (PARKINSON’S DISEASE) AND MOVEMENT DISORDERS.

- Side effects of drugs that influence nutritional status in PD.
- Is there a role for protein redistribution diet in PD patients on dopaminergic treatment?
- Does nutritional support improves QoL / survival of PD patients?
- What is the clinical relevance and natural history of OD in other movement disorders (PSP, Chorea, etc)
3. Nutritional support in demyelinating diseases (with special attention to Multiple Sclerosis, MS)

Specific issues
NUTRITIONAL SUPPORT IN DEMYELINATING DISEASES (WITH SPECIAL ATTENTION TO MULTIPLE SCLEROSIS, MS)

- Is there a role for a dietary prevention of MS? (list of specific nutrients involved in MS to facilitate retrieval of articles)

- Can nutritional support decrease the rate and severity of relapses in MS patients?

- Does nutritional intervention improve nutritional status in MS patients?

- Can nutritional support improve QoL / survival in MS patients?
GLOBAL ISSUES FOR OROPHARYNGEAL DYSPHAGIA IN PATIENTS WITH NEURODEGENERATIVE DISEASE

• What are the most appropriated dysphagia screening tools for patients with neurodegenerative diseases?

• Diagnosis of dysphagia.
  – What is the role of clinical methods in the diagnosis of dysphagia in neurodegenerative patients?
  – What is the role of videofluoroscopy in the diagnosis of dysphagia in neurodegenerative patients?
  – What is the role of fiberoptic endoscopic evaluation in the diagnosis of dysphagia in neurodegenerative patients?
GLOBAL ISSUES FOR OROPHARYNGEAL DYSPHAGIA IN PATIENTS WITH NEURODEGENERATIVE DISEASE

• Treatment of dysphagia
  – What is the role of dietary treatment of neurogenic dysphagia?
    • Modified consistency diets (solids and fluids, rheology, consistencies and viscosity)
    • Oral nutritional supplementation.
    • Enteral nutrition. Can tube feeding prevent aspiration pneumonia in neurodegenerative patients?
  – What is the role of swallowing therapy in the treatment of neurogenic dysphagia in neurodegenerative patients?
  – Specific aims for specific diseases.
  – New neurorehabilitation methods (surface electrical stimulation, magnetic stimulation, etc)
5. Ethical issues
ETHICAL ISSUES

• Role of advanced care directives in nutrition support in ND diseases.

• Ethical concerns about withdrawal or withholding SNS in advanced patients.
WHERE ARE WE NOW?

3.5. Step 5: literature retrieval

The formal process of literature retrieval will be launched during the second half of the live meeting. Relevant Medical Subject Headings (MeSH) and additional keywords will be listed by the GDG, with the participation of a GLC member. This list will be sent to a subcontractor, in charge of searching medical databases (PubMed, EMBASE, OVID, Scopus, Cochrane) for original articles containing an abstract in English and 1st-degree related articles. The list of abstracts will be sent to the GDG chair and the GLC. The GDG chair will manage the selection of relevant articles. A flow chart outlining the reasons for exclusions of articles will be drawn. The full-length selected articles will be provided by the GLC to the members of the GDG.

3.6. Step 6: formal assessment of specific questions

A list of specific issues relevant to the areas and topics previously agreed (step 2) will be developed by the GDG and validated by the GLC. The available evidence useable to answer these issues will be assessed from the available literature by the GDG using the GRADE classification. When applicable, systematic review and/or meta-analysis of the data and a summary of these analyses will be carried out by the subcontractor.
THANK YOU FOR YOUR ATTENTION
SEE YOU IN GENEVA