WG 4

Euromene meeting,

Belgrade 7th of Sept. 2017

WG4 members

- Elin Strand (leader, Norway)
- Francois Authier (vice leader, France)
- Ingrid Helland (Norway)
- Patricia Grabowski (Germany)
- Luis Nacul (UK)
- Angelica Krumina (Latvia)
- Jose Allegre (Spain)
- Anne Marit Mengshoel (Norway)

Overall objective: develop an European standard for diagnosis and clinical treatment

WG4: TASKS FOR THE FIRST PERIOD OF THE PROJECT

- Survey clinical criterions used in EU countries to set-up diagnosis of ME/CFS
- Analyse existing clinical criterions guidelines in order to find-out optimal criteria set allowing excluding over-diagnostic and un-diagnostic;
- Survey in EU countries existing data on neurological picture of ME/CFS (including association with similar diseases and symptoms, like fibromyalgia)
- Analyse the used ME/CFS treatment and its efficacy/safety in order to find-out optimal treatment approaches lowering severity of clinical course.

What have we done

- Survey among Euromene countries (N=14)
- Decision on diagnostic criteria
- Decision on symptom registrations/classification tools
- Assessment among 6 countries:
  - other health (topic) information
  - Questionnaires/tools used for other health information

Desicions on criteria, questionnaires and management

- Canadian Consensus criteria 2003 (Fukuda/IOM)
- Exclusion (Canada criteria, Reeves et al 2003)
  - Somatic examination
  - Psychiatric/psychological examination

Decisions on asessmens/instruments for other health information

- Symptom registrations
  - DePaul Symptom Questionnaire
  - SF-36 (free version)
  - HADS
- asessments/questionnaires for other health information (survey)

Theme being registered, common to several countries

- Demografics
- Symptoms
- Physical functioning level (50% reduced)
- Anxiety/depression/mental health
- fatigue
- Sleep problems
- Cognitive functioning
- Pain
- Neurevegetative symptoms
- Cognitve dysfunction
- UK: self/familiy health, health history, work, mood, activity etc

Data collection on other patient groups

- **Spain:** cancer curvivors, MS, RA. Viral infection, overtraining syndrome, idiopatic chronic fatigue
- **UK:** MS, HC
- **Norway:** HC (idiopatic CF)
- **Germany:** cancer related fatigue, POTS, overtraining syndrome, post infectious CF, HC
- **Italy:** CFS-pediatric patients, MS

- Treatments (symptom relief, symptomreduction, cure)
- Symptom (self-) management and ilness coping
  - All strategies that would increase self-management, coping and quality of life
  - CBT, GET, Pacing, other strategies
  - Review from Spain

Review paper from JC`s group (2017)

BJP British Journal of Pharmacology

British Journal of Pharmacology (2017) •• ••–•• 1

REVIEW ARTICLE

Treatment and management of chronic fatigue syndrome/myalgic encephalomyelitis: all roads lead to Rome

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This review explores the current evidence on benefits and harms of therapeutic interventions in chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) and makes recommendations. CFS/ME is a complex, multi-system, chronic medical condition whose pathophysiology remains unknown. No established diagnostic tests exist nor are any FDA-approved drugs available for treatment. Because of the range of symptoms of CFS/ME, treatment approaches vary widely. Studies undertaken have heterogeneous designs and are limited by sample size, length of follow-up, applicability and methodological quality. The use of rintatolimod and rituximab as well as counselling, behavioural and rehabilitation therapy programs may be of benefit for CFS/ME, but the evidence of their effectiveness is still limited. Similarly, adaptive pacing appears to offer some benefits, but the results are debatable: so is the use of nutritional supplements, which may be of value to CFS/ME patients with biochemically proven deficiencies. To summarize, the recommended treatment strategies should include proper administration of nutritional supplements in CFS/ME patients with demonstrated deficiencies and personalized pacing programs to relieve symptoms and improve performance of daily activities, but a larger randomized controlled trial (RCT) evaluation is required to confirm these preliminary observations. At present, no firm conclusions can be drawn because the few RCTs undertaken to date have been small-scale, with a high risk of bias, and have used different case definitions. Further, RCTs are now urgently needed with rigorous experimental designs and appropriate data analysis, focusing particularly on the comparison of outcomes measures according to clinical presentation, patient characteristics, case criteria and degree of disability (i.e. severely ill ME cases or bedridden).

Abbreviations

APT, adaptive pacing therapy; CBT, cognitive behavioural therapy; CDC, Centres for Disease Control and Prevention; CFS/ME, Chronic fatigue syndrome/myalgic encephalomyelitis; CoQ_{10}, Coenzyme Q_{10}; DHA, docosa; EPA, eicosapentenoic acid; FINE, Fatigue intervention by nurses evaluation trial; GET, graded exercise therapy; GLA, γ-linolenic acid; HADS, Hospital anxiety and depression scale; Max HR, maximum heart rate; ICC-ME, 2011 International Consensus criteria for ME; IOM, Institute of Medicine; NSAIDs, Non-steroidal anti-inflammatory drugs; PACE, Pacing, graded activity, and cognitive behaviour therapy; a randomized evaluation for CFS patients; PVFS, Post-viral fatigue syndrome; RCT, randomized controlled trial; SEID, systemic exertion intolerance disease; SMC, standard medical care; SSRI, selective serotonin-reuptake inhibitor; SSNRI, selective serotonin-noradrenaline reuptake inhibitor

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Plan for the next year

- Finished survey
- Write a report (deliverables and minutes from the meeting)

Objectives for the next year

- Translate into English or in other ways review the three national guidelines or part of them (Norway*, Italy and Spain)
- Assessments and questionnaires for sampling non biological health information (ongoing work)
- Look closer into CCC exclusion criteria, might be changed or further specified
- Review studies on symptom relief
- neuroimmunological studies/cognitive tests (Jerome)
- Write a paper (all)?