

WHAT ARE THE DIFFERENCES BETWEEN ME AND CFS?

Definitions and Explanations - Useful ways to diagnosis

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The status of and future research into Myalgic
Encephalomyelitis and Chronic Fatigue Syndrome

Need of accurate diagnosis, objective assessment, and
acknowledging biological and clinical subgroups

Myalgic Encephalomyelitis versus Chronic Fatigue Syndrome

- ME and CFS are used interchangeably, but...
- Diagnostic criteria define 2 distinct clinical entities
- Chronic fatigue : subjective and ambiguous notion
- Unexplained (persistent or relapsing) chronic fatigue is the basis of the problem, but...

ME – the symptoms

- Cognitive impairment (brain fog)
- (Muscle) weakness
- Circulatory disturbances
- Marked variability of symptoms
- above all, **post-exertional malaise**: a long-lasting increase of symptoms after a minor exertion



ME is a neuro-immune illness

Differences

- “Fatigue” not obligatory for ME diagnosis
- Post-exertional malaise and cognitive deficits not mandatory for the diagnosis of CFS but obligatory for the diagnosis of ME

Differences

<i>Symptom</i>	Chronic Fatigue	ME / SEID
Fatigue	YES	NOT always
Post-Exertion Malaise	NOT mandatory	YES
Cognitive deficits	NOT mandatory	YES

Differences

- The distinction between patients with or without post-exertional malaise is reflected by particular clinical and immunological differences

(Maes et al., 2012; Brenu et al., 2013)

A CLINICAL ASSESSMENT OF ME / CFS SHOULD BE BASED UPON OBJECTIVE MEASURES

Several distinctive symptoms can be
assessed objectively

Objective Assessment Tests

Symptom

- Loss of Energy / Weakness
- Cognitive deficit
- Muscle weakness
- Orthostatic intolerance
- Visual symptoms

- Defective stress response

Test

- Cardiopulmonary Exercise Test
- Specific neurocognitive tests
- Muscle power and endurance tests
- Tilt table test
- Useful field of view, eye movements tests

- Hormonal investigation

Objective Assessment Tests

Symptom

- Post Exertional Malaise
 - Physical
 - Cognitive
- Sleep disturbances

Test

- PEM
 - Repeated CPET, after 24 hours
 - Specific neurocognitive tests
- Polysomnographic investigation

Abnormalities in ME / CFS 1/4

- **Immunological aberrations** (inflammation, immune activation, immuno-suppression and dysfunction)
 - Usually observed during (latent) infection
 - Intestinal **dysbiosis**, inflammation and hyperpermeability
 - Associated with systemic immune system abnormalities

Abnormalities in ME / CFS 2/4

- Reactivating and/or persistent infections
- Elevated oxidative and nitrosative stress
- Mitochondrial dysfunction and damage

Abnormalities in ME / CFS 3/4

- Hypovolemia, diminished cardiac output, blood and **oxygen supply deficits** to muscles and brain especially in an upright position and during exercise
- Reduced (maximum) oxygen uptake
- Neurological abnormalities

Abnormalities in ME / CFS 4/4

- Hypo-cortisolism / blunted hypothalamic-pituitary-adrenal (HPA) axis response
- Ion channel dysfunction (channelopathy)
- **Deviant physiological responses to exertion**

CONCLUSIONS

What are the key points for the future research?

Recommendations for the future

1. Post-exertional “malaise” should define two separate clinical and research entities
2. Symptoms of ME/SEID and CFS should be assessed objectively as much as possible

Recommendations for the future

3. **Biomarkers** should be used to distinguish biological subtypes in research
4. Trials into the efficacy of therapies should use **objective measures** to establish the effects of therapies

For example

- positive change in the oxygen uptake
- cognitive tests scores

The key points in the work of Frank Twisk

- Clear distinction between 2 entities: CFS and ME/SEID
- Review on clinical and biological assessment tools
- Sub-groups of patients mandatory for future research
- Control of efficacy – **objective measures** and biomarkers

At the Dead Sea Rehabilitation Center

- Patient-oriented (individual) treatment
- Multidisciplinary rehabilitation program
- Climatotherapy under medical supervision
- CBT and psycho-social activities

- BUT ... No possibility to clinical follow-up !

At the Dead Sea Rehabilitation Center

- Groups of patients
- 10-year experience
- Excellent success rates
- Possibility to check immediately biological changes
- Research Center

After the Dead Sea Rehabilitation Center

Objective criteria for success evaluation

- Return to normal life
- Back to cognitive activities
- Back to work, school or studies
- No need of medical support

After the Dead Sea Rehabilitation Center

A necessity : cooperation with Norwegian Universities

Objective assessment

Clinical tests and biomarkers

Long-term follow up

THANK YOU !
