How to categorize ME and CFS

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This document is a brief sketch for further discussion on how to proceed with taxonomy in research related to Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS).

Taxonomy

There is a problem when using the term CFS, because it has so many different meanings depending on the definition used. A taxonomy is proposed for use in for example scientific articles, so language will not become excessively complicated when talking about the different types of CFS.

ME-Ramsay	Myalgic Encephalomyelitis as described by Melvin Ramsay
ME-Hyde	Myalgic Encephalomyelitis as defined by Byron Hyde
ME/CFS-2003	Canadian clinical criteria 2003
CFS-Holmes	Holmes research criteria 1988
CFS-Fukuda	Fukuda research criteria 1994
CFS-Reeves*	Reeves definition 2005

*Note: CFS-Reeves is proposed to be renamed to something else, for example "Reeves illness melange" (RIM), as motivated below.

Hostile take-over

Reeves et al has managed to hijack the CFS term introducing a whole new definition [1] that has very little to do with the initial meaning of CFS in the Holmes criteria [2]. I think now patient organizations and ME-researchers must protest to the fact that Reeves group and CDC took over the CFS term and replaced it with an other meaning. Reeves definition should not have been allowed to be referred as CFS, but instead for example "Reves illness melange".

Unfortunately, it seems to late to make Reeves and CDC to back off because some articles have already been published under the term CFS using the Reeves definition. Also, CDC has already put it on their internet site. The only thing we can do is to change to a different term, but indeed letting our voices be heard, so it will not happen again and in order to make researchers and medical doctors to be aware of the change of meaning with CFS introduced by CDC and Reeves. New and older articles can not be compared because the patient populations are selected differently.

I wonder if it is possible at all for Reeves to refer to a "syndrome" for his definition. A syndrome is a collection of symptoms running together defining a disease, but as I understand it, the Reeves definition is not symptom oriented, but rather oriented on achieving higher scores on psychosocial question formularies. It does not require the condition to be chronic as it only looks one month back in time while earlier definitions (CFS-Holmes and CFS-Fukuda) have required the condition to be present at least 6 months.

Definitions in research

There has been some trouble with the Fukuda definition in not being strict enough, but indeed some progress in biomedical research has been made with this definition over the past 20 years. It is not recommendable to switch a definition from one day to an other, because that will result in new and previous research not being possible to compare.

My proposal is that research in ME shall be made according on a strict definition. It is better to research on a stricter definition than a looser. Why? A too loose definition will not help any patient because it will be too difficult to find any statistical significant differences for a heterogeneous group. A too strict definition might leave some patients "outside" in the scientific studies, but they ultimately will be helped by a faster progress in the scientific research.

Now we are coming closer to where biomedical discoveries can help us to untangle the heterogeneity in ME/CFS research. I think it is the wrong time to introduce a new criterion, especially if it a broadening. What can be done is to sub-group instead. Sub-group on symptoms, infections and biomedical variables. Stratify or correlate with time of disease and severity (level of invalidity).

If a change of criteria shall be made, then it is necessary to use the old and new criteria in parallel in scientific studies for a period of several years (~10 years) in order to keep comparability. This means that if one for example would like to change to the Canadian 2003 criteria, one should group the patients in the following manner:

1. The ones only fulfilling the Canadian criteria
2. The ones only fulfilling the Fukuda criteria
3. The ones fulfilling both the Canadian and Fukuda criteria

That solution will make it possible to work with a stricter criteria, but at the same time to keep the comparability with previous studies.

Requests on scientific articles

- No article should ever be published about CFS without stating the definition used clearly in the abstract.
- No article should be allowed to use CFS as a term for the Reeves definition. Instead the term "Reeves Illness Melange" definition (RIM) shall be used.
- The level of invalidity of the cohort shall also be stated in the abstract.
- The number of patients with post-exertional malaise exceeding 24 h in the cohort shall always be stated.

WHO categorization

WHO must state that Reeves definition is not valid for using the WHO ICD-10 code G93.3. Otherwise the G93.3 will be misused for something that has nothing to do with its original meaning. The statistics will be wrong and misleading.

To be classified G93.3

- Myalgic Encephalomyelitis as described by Melvin Ramsay, E.G. Dowsett, and E.D. Achesson.
- Canadian clinical criteria 2003
- Holmes research criteria 1988
- Fukuda research criteria 1994 with additional obligatory symptoms of post-exertional malaise exceeding 24 h, dysfunction of thermoregulation, and cerebral dysfunction

<u>Not</u> to be classified as G93.3

- Reeves definition 2005

References

[1] Reeves WC, Wagner D, Nisenbaum R, Jones JF, Gurbaxani B, Solomon L, Papanicolaou DA, Unger ER, Vernon SD, Heim C. Chronic fatigue syndrome--a clinically empirical approach to its definition and study.b BMC Med. 2005 Dec 15

[2] Holmes et al.. Chronic Fatigue Syndrome: A Working Case Definition. Ann Intern Med. 1988; 108:387-389.