CFS is no longer CFS, and it was never ME

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The Centres for Disease Control and Prevention in the USA has adopted a more including criterion for chronic fatigue syndrome which is important to be aware of when reading scientific papers. It is important to know that the new criteria is so much "loosened up" that it encompasses 2,5% of the general population instead of around 0,4% as with the earlier criteria. How to stratify and group patients in future research is proposed. The use of disjoint sets of patients is encouraged.

Abbreviations
CDC  Centres for Disease Control and Prevention, USA.
CFS  Chronic Fatigue Syndrome
et al.  et alii (Latin) = and others
ME  Myalgic Encephalomyelitis

ME research
The Centres for Disease Control and Prevention in the USA (CDC) has adopted the Reeves (et al.) empirical definition of CFS from 2005 [6], after having used the Fukuda definition since 1994 [5]. The Fukuda definition was already not good for research into Myalgic Encephalomyelitis (ME) because it did not have important ME symptoms as mandatory. It was e.g. possible to have patients with depression (without ME) fulfilling the Fukuda definition.

The CDC states that ME is not the same thing as chronic fatigue syndrome [3]. This is correct because "the father of ME", Melvin Ramsay from England, was never member of the group that created the first CFS criterion 1988 for CDC (Holmes et al.)[4]. Ramsays description of ME included muscle phenomena, circulatory impairment and cerebral dysfunction [1]. These things are not required for any of the CDC CFS definitions [4][5][6].

The last years very little biomedical research has been made on ME with a strict ME definition, but ME patients have hoped that the use of the Fukuda definition in research, if used with care, indeed collects sufficient ME patients to get statistical significant results. Nevertheless, one must be aware that it is possible to produce a study with patients fulfilling the Fukuda definition without anyone having ME. E.g. it is possible for some people with depression to fulfil the Fukuda definition.

In my experience, all patients with ME complain about cognitive problems, temperature regulatory problems and post exertional malaise exceeding 24 h. Most ME patients have sleep dysfunction and intolerances to pharmaceutical drugs. Their cognitive function worsens with upright posture. These symptoms are not required for any of the CDC CFS criteria [4][5][6].

The Canadian definition requires for example post exertional malaise exceeding 24 h and sleep dysfunction, but circulatory impairment is not a mandatory symptom, making it different from the Ramsay definition [1].

Biomedical research into ME at risk
The situation has changed to the worse for ME research since 2005 when Reeves and others from CDC created a so called empiric definition for CFS. The problem is that it collects a more vast group of patients. With the Fukuda criterion the estimated prevalence is 0,4%, but with the Reeves definition the prevalence is 2,5% [7]. The Fukuda criterion already defines a heterogeneous group of patients, and one would wish that a more strict criteria is used, but instead one expands the group further so the CFS-Fukuda patients are in minority, only representing 15% of the CFS-Reeves group. Leonard Jason has criticized the CFS-Reeves criterion [8][9].

1(3)
Below is a list of research that already have been made with the new loose and fuzzy CFS-Reeves definition. The list has been compiled by Tom Kindlon. Many people are not aware the fact that these articles are based upon a different definition, because many of the articles have obscured what kind of criteria that has been used. Science should be transparent and clear, but unfortunately articles have been accepted despite it requires quite some work in order to figure out which criteria that was used.

Since the CFS-Reeves definition started to be used, it is quite a mess. It is work demanding to sort out which article has used which definition, and what definition that have been used in the articles that the article refers to. Ultimately this puts the validity of the research at risk.

If things would work properly in the scientific world, CFS-Reeves should have been called something else than CFS, because it is a supergroup to something that is already defined. It is like calling all mammals for apes. Only because apes are a subgroup of mammals, it does not mean that all mammals are apes.

**Suggestions for future research**

Many ME patients around the globe are waiting for research that will lead to meaningful results, an understanding of the pathophysiology and pathogenesis, and ultimately a cure. The research is based on the very important decision of how to group the patients, therefore this shall not be performed with heedlessness.

The expansion of the CFS concept is a severe disappointment for patients with ME that are hoping that biomedical research will progress. Scientists are urged not to use the CFS-Reeves definition, instead using the limited resources in order to advance ME research.

It would be an advantage if it would be possible to use exclusive sets of patients (disjoint sets). For the already heterogeneous CFS-Fukuda set, it would be a benefit if one could exclude the ME-Ramsay (or ME/CFS-Canada) patients from the group, thus making it less heterogeneous. The excluded ME patients shall then form a separate group. In order to keep comparability to previous research, one should indeed also have a group based on the original CFS-Fukuda definition, during a time period of around 10 years.

Scientists are suggested to group patients as follows in the future:

2) Patients fulfilling CFS-Fukuda [5] and do not fit into group 1.
3) Patients from both group 1 and 2 above, i.e. patients fulfilling CFS-Fukuda.

* Note: One of the three definitions proposed in group 1 above should be agreed upon using. The meaning is not to use all three simultaneously.

This solution would be helpful to the patients that have ME, but also to the patients that do not have ME but still CFS. A win-win situation for both group of patients, because it will most likely speed up biomedical research.

The severity of ME can vary greatly, therefore it is strongly recommended that data is stratified upon severity.

**References**


[3] CDC citation: "The name myalgic encephalomyelitis (ME) was coined in the 1950s to clarify well-documented outbreaks of disease; however, ME is accompanied by neurologic and muscular signs and has a case definition distinct from that of CFS." [http://www.cdc.gov/cfs/cme/wb3151/chapter1/overview.html](http://www.cdc.gov/cfs/cme/wb3151/chapter1/overview.html)


List of articles based upon the CDC Reeves 2005 CFS criteria

Source Tom Kindlon (http://listserv.nodak.edu/cgi-bin/wa.exe?A2=ind0706D&L=CO-CURE&P=R1422&I=-3&n=17418)


