The Terminology of ME & CFS

By
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Terminology

The term BENIGN MYALGIC ENCEPHALOMYELITIS was first introduced in the UK in 1956 by a former Chief Medical Officer (Sir Donald Acheson) and not by Dr Melvin Ramsay as is sometimes claimed. The word "benign" was used because it was thought at the time that the disorder was not fatal (as poliomyelitis could be, with which it had some similarity), but it was quickly realised by clinicians that ME was not a "benign" condition, as it has such high morbidity (ie. such a lot of suffering and ill-health), so by 1988 clinicians had stopped using the word "benign" and referred to it as ME, the first to do so being Dr Ramsay. However, the ICD still uses the term "benign" in its classification.

MYO relates to muscle
MYOSITIS = inflammation of muscle
MYALGIA = pain in muscles (pain that is called "myalgic")
MYOPATHY = any disease or disorder of muscle
MYEL (or MYELO) relates to the spinal cord (the main nerve in the body)
MYELITIS = inflammation of the spinal cord (NB. Not to be confused with the other meaning of myelitis, which = inflammation of the bone marrow, as in osteomyelitis)
MYELIN SHEATH = a layer of fatty white material that surrounds and insulates nerve fibres
DEMYELINATION = the loss of this protective insulation round nerve fibres (as seen in multiple sclerosis and sometimes also in ME)
ENCEPHALON = the brain
ENCEPHALO = relating to the brain
"ITIS" on the end of a word = inflammation (eg. hepatitis = inflammation of the liver)

SO---- ENCEPHALOMYELITIS = inflammation of the brain and spinal cord

BENIGN MYALGIC ENCEPHALOMYELITIS therefore means a non-fatal disorder (inflammation) of the brain and spinal cord, with pain in the muscles

ENCEPHALOPATHY = any non-inflammatory disorder affecting the brain
Despite the claims of some psychiatrists, it is not true that there is no evidence of inflammation of the brain and spinal cord in ME: there is, but these psychiatrists ignore or deny that evidence. For example:

1988 In conjunction with the University of Pittsburgh, the US NIAID held a large research workshop called "Consideration of the Design Studies of Chronic Fatigue Syndrome". There were participants from the Centres for Disease Control and from the National Institutes of Health. One of the presentations was by Dr Sandra Daugherty, who reported that MRI scans on patients demonstrated abnormalities consistent with demyelination and cerebral oedema in 57% of patients studied. (It was at this conference that it was recommended that the term "CFIDS" be used instead of the term "CFS" on the basis of the immune dysfunction that had been observed in the disorder).

1989 Detection of Viral-Related Sequences in CFS Patients using Polymerase Chain Reaction W.John Martin (Nightingale Research Foundation: 1989: 1-5
1990 Chronic Fatigue Syndrome and the Psychiatrist SE Abbey, PE Garfinkel Canadian Journal of Psychiatry 1990:35:7:625-626
1992 A Chronic Illness Characterised by Fatigue, Neurologic and Immunologic Disorders, and Active Human Herpesvirus Type 6 Infection D Buchwald, PR Cheney, R Gallo, AL Komaroff et al Annals of Internal Medicine 992:116:2:103
This paper states "Magnetic resonance scans of the brain showed punctate, subcortical areas of high signal intensity consistent with oedema or demyelination in 78% of patients"
1994 Detection of Intracranial Abnormalities in Patients with Chronic Fatigue Syndrome: Comparison of MR Imaging and SPECT. RB Schawrtz, BM Garada American Journal of Roentgenology 1994:162:935-941
1995 Pathophysiology of a Central Cause of Post-Polio Fatigue Richard Bruno et al Annals of the New York Academy of Sciences 1995:753:257-275
1997 A 56-year old woman with chronic fatigue syndrome Anthony J Komaroff JAMA 1997:278:14:1179-1184

It is true that there is no evidence of inflammation of the brain or spinal cord in states of chronic fatigue or "tiredness."

It is also true that neither the 1991 (Oxford) criteria nor the 1994 (CDC) criteria select those with ME, as they both expressly include those with somatisation disorders and they expressly exclude those with any physical signs of disease (as is the case in ME), so by definition, patients with signs of neurological disease have been excluded from study.

It is also true that Professor Simon Wessely and his colleagues use the terms "fatigue", "chronic fatigue", "the chronic fatigue syndrome (CFS)" and "myalgic encephalomyelitis (ME)" as synonymous. Such obfuscation has greatly hindered research, as pointed out in the 1994 Report of the National Task Force on Chronic Fatigue Syndrome (CFS), Post-Viral Fatigue Syndrome (PVFS) and Myalgic Encephalomyelitis (ME), published by Westcare, Bristol and supported by the UK Department of Health, which stated:

"Chronic fatigue syndromes remain poorly understood. Progress in understanding them is hampered by:

- the use by researchers of heterogeneous study groups
- the use of study groups which have been selected using different definitions of CFS
- the invalid comparisons of contradictory research findings stemming from the above".

The Report names psychiatrists Dr Simon Wessely, Dr Peter White and Dr Michael Sharpe and acknowledged their help, but then makes the point that "people who gave their help are not necessarily in agreement with the opinions expressed" (page 87). It was said to be because those psychiatrists strongly disagreed with the findings of the 1994 Westcare Report that in 1996 they produced their own report (the Report of the Joint Royal Colleges on CFS (CR54), which was internationally recognised as being biased and seriously flawed).

Classification

The WHO was founded in 1948.

The International Classification of Diseases (ICD) comes in two volumes: Volume I is the Tabular List and is a list of codes plus the name of the condition which goes with that code. Volume II is the Code Index, which alphabetically lists all the phrases and names of conditions commonly used for a condition, together with the appropriate code.

The Tabular List (Volume I) does not list everything which is in the Code Index (Volume II)

Benign myalgic encephalomyelitis (ME) has been classified in the International Classification of Diseases (ICD) as a neurological disorder since 1969, when it was included in ICD-8 at Volume I: code 323: page 158 and in Volume II (the Code Index) on page 173. (ICD-8 was approved in 1965 and published in 1969).

Prior to 1969, the term benign myalgic encephalomyelitis (ME) did not appear in the ICD, but non-specific states of chronic fatigue were classified with neurasthenia under Mental and Behavioural Disorders.

Benign myalgic encephalomyelitis (ME) was included in ICD-9 (1975) and is listed in Volume II on page 182.

The term "Chronic Fatigue Syndrome" was not introduced by Holmes et al until 1988 and therefore did not appear in the ICD until 1992, when it was listed as an alternative term for benign myalgic encephalomyelitis (ME). Another alternative term listed is Post-Viral Fatigue Syndrome.

In ICD-10 (1992), benign myalgic encephalomyelitis (ME) continues to be listed under Disorders of the Nervous System at G93.3, with the term Syndrome, Fatigue, Chronic, as one of the descriptive terms for the disorder.

By contrast, in ICD-10 (1992), neurasthenia and other non-specific syndromes of on-going or chronic "fatigue" are listed at section F48.0 (Volume I, page 351). Non-specific states of chronic fatigue are classified as Mental and Behavioural Disorders, subtitled "Other Neurotic Disorders".

Note: benign myalgic encephalomyelitis (ME/CFS/PVFS) is expressly excluded by the WHO from this section.

Note also that the WHO has confirmed in writing that "it is not permitted for the same condition to be classified to more than one rubric as this would mean that the individual categories and subcategories were no longer mutually exclusive".

Therefore, ME/CFS cannot be known as or included with neurasthenia or with any mental or behavioural disorder.

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