SCIENCE or SEMANTICS?

Margaret Williams

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In his capacity as Medical Advisor to the Sussex and Kent ME/CFS Society, Professor Anthony Pinching provided his comments on "Fibromyalgia and CFS/ME" (Co-Cure 7th December 2004) but whilst acknowledging that the terminology is confusing he notably did not mention the evidence that helps to clarify the confusion, for example:

- 1) Fibromyalgia has been well documented for the last 150 years and has a uniform set of symptoms and signs that can be readily distinguished from other causes of chronic musculo-skeletal pain (Ref. Fibromyalgia and Related Syndromes, DL Goldenberg. In: Rheumatology Klipper and Drieppe 2nd edition 1998).
- **2**) Fibromyalgia is classified as a discrete entity by the World Health Organisation ICD-10 at M79.
- **3**) In his Update of August 2003 entitled "Improving Services for Patients" the UK Chief Medical Officer referred to Fibromyalgia as a medical entity.
- **4**) Fibromyalgia is recognised as a serious systemic disorder ie it is much more than chronic musculo-skeletal pain.
- 5) Whilst there is certainly some overlap in symptomatology with ME/ICD-10 CFS, there are significant differences including:

1991: in spite of some overlap, FM and ME/CFS do not represent the same syndrome. (Primary fibromyalgia and the chronic fatigue syndrome. AJ Wysenbeek et al Rheumatology Int 1991:10:227-229)

1996: "fibromyalgia appears to represent an additional burden of suffering amongst those with (ME)CFS" (Fibromyalgia and Chronic Fatigue Syndrome - similarities and differences. Dedra Buchwald and Deborah Garrity. Rheum Dis Clin N Am 1996:22:2:219-243)

1997: levels of somatomedin C are lower in FM patients but higher in ME/CFS patients (Somatomedin C (insulin-like growth factor) levels in patients with CFS. AL Bennett, AL Komaroff et al. J psychiat Res 1997:31:1:91-96)

1998: "recent studies suggest that (co-existent FM and (ME)CFS) may bode much more poorly for clinical outcome than CFS alone. In contrast to (significantly) elevated CBG (cortisol binding globulin) levels in patients with CFS, no differences were observed in FM patients. Differences in secretion of AVP may explain the divergence of HPA axis function in FM and (ME)CFS" (Evidence for and Pathophysiologic Implications of HPA Axis Dysregulation in FM and CFS. Mark A

Demitrack and Leslie J Crofford. Ann New York Acad Sci 1998:840:684-697)

1998: there is no evidence for elevated Substance P in patients with ME/CFS, whereas levels are elevated in patients with FM (CFS differs from FM. No evidence for altered Substance P in cerebrospinal fluid of patients with CFS. Evengaard B et al Pain 1998:78:2:153-155)

2001: patients with FM are NOT acetylcholine sensitive (Investigation of cutaneous microvascular activity and flare response in patients with fibromyalgia. AW Al-Allaf, F Khan, J Moreland, JJF Belch. Rheumatology 2001:40:1097-1101)

2004: patients with ME/CFS ARE acetylcholine sensitive (Acetlycholine mediated vasodilatation in the microcirculation of patients with chronic fatigue syndrome. VA Spence, F Khan, G Kennedy, NC Abbot, JJF Belch Prostaglandins, Leukotrienes and Essential Fatty Acids 2004:70:403-407)

2003:endothelin-1 is RAISED in fibromyalgia (Increased plasma endothelin-1 in fibromyalgia syndrome. Pache M, Ochs J et al Rheumatology 2003:42:493-494)

2004: endothelin-1 is NORMAL in ME/CFS (Plasma endothelin-1 levels in chronic fatigue syndrome. Kennedy G , Spence V, Khan F, Belch JJF Rheumatology 2004:43: 252-253)

- **6**) The recommended management approach for Fibromyalgia includes a minimum of 30 minutes of aerobic exercise three times per week but such an approach could be actively harmful for people with ME/ ICD-10 CFS
- 7) Whiting et al expressly excluded Fibromyalgia from the York Systematic Review of the literature of management approaches that might be helpful for "CFS/ME". (Ref. Interventions for the Treatment and Management of Chronic Fatigue Syndrome. Penny Whiting et al. JAMA 2001:286:11:1360-1368).
- **8**) Whilst Professor Pinching correctly draws attention to confusing terminology, is it not curious that he makes no mention of the existing published evidence that serves to unravel the perceived confusion?