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A video of the presentation can be viewed here: <https://youtu.be/JWsFvmuJxMA>

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Presentation: Professor Peter White, Bart's and the London School of Medicine

What is Chronic Fatigue Syndrome and what is ME?

29.00 minutes duration

Transcript of first 6:55 minutes of presentation: 08.02.09

0.00

Well, good morning ladies and gentlemen, I'm very pleased to have the honour of kicking off the conference, and you notice my colleagues have given me the easiest topic of defining what the illness is. Now let's just see if I can make this work. So, I'm going to cover this area in the next twenty-five minutes, allowing time for questions at the end. I'm going to try to define what Chronic fatigue syndrome is. By doing so, I'm going to review the ICD-10 criteria for the illness and see if they're helpful. The answer will be, they are not helpful. I'm going to look at research criteria to see if they help us try and define this illness in the clinical aspect. But this meeting is about clinicians making the diagnosis and helping patients. And the answer is, the research criteria are pretty useless at defining the illness clinically. So we then come to the three clinical criteria at the end to see if they're useful and two of them actually do have help to us; so the good news is, after some attrition as we skim through ICD-10 research criteria, there will be some good news at the end, where there are two particular clinical criteria: the NICE Guidelines criteria and the Royal College Of Paediatrics and Child Health criteria I would commend to you, as clinicians, as a useful way of starting the process of diagnosis and management to your patients.

1:26

But nothing is simple, as Albert Einstein said. You've got to keep things simple but no simpler in life, so there is a bit of a twist in the tail at the end of CFS, where we have the Wessely/White debate - is there *one* functional somatic syndrome; is CFS part of actually a wider, one functional somatic syndrome that includes things like IBS, Fibromyalgia and things like that, or is it the opposite polar extreme: that chronic fatigue syndrome is more than one illness - it's actually heterogeneous? So I'm going to just touch on that. And at the end of my talk, I'm going to try and perhaps answer an even more difficult question: what is ME? And I'm going to go back to the original descriptions of ME, back to the 1950s to help us and also make the point - which is another important clinical point - that I'm going to make this morning, that is, the diagnostic labels we choose to use influence our patients and influence prognosis. If I have time - I may not.

2.27

I'm going to make the broader point – patients come in and they say to us, "What is ME. Does it really exist?" Or if it's CFS, "Does it really exist?" The answer is, yes, it does exist and "Is it physical or mental?" And unfortunately we live in a Cartesian world of dualism: it's either mental or it's physical. The reality, of course is, anyone with an understanding of neuroscience will know, as we will in this audience, actually it's both: physical and mental, and you cannot divide the mind from the body. So let's see, we'll start with "The Mystery". There's no doubt this is a mysterious illness, as John Scadding has already implied, and we do have a problem with what we call it. *[Reads from media article] "Once dismissed as 'yuppie flu,' chronic fatigue is increasingly recognised as a debilitating disease that affects millions."*

3.18

And one of our problems is: labels do count. So "Yuppie Flu"? If you were told you that you suffered from "Yuppie Flu", how would you feel? So we do have a problem in how we label. And also it's a problem that we have partial responsibility for, as doctors and health care professionals. From another magazine: *"If your doctor says it's all in the mind...", would you like to be told it's all in your mind? "...don't assume you're just neurotic." Notice the word "just." "You may be suffering from one of the 'new' illnesses that doctors are still having difficulty diagnosing."* And as you'll see from my talk, today, we are still struggling to make the diagnoses of Chronic fatigue syndrome and ME. So we are partially responsible for what is going on.

3:54

So, does the ICD-10 help us? Unfortunately not; there at least five ways (in fact there are probably more than five) of classifying Chronic fatigue syndrome using the ICD-10 criteria.

What are they? We start off well: Myalgic encephalomyelitis is in the neurology chapter of ICD-10. Its main title is "Post viral fatigue syndrome" and subsumed under that is "Benign myalgic encephalomyelitis" and helpfully, "Chronic fatigue syndrome (postviral)." So it starts off well. You get a virally triggered chronic fatigue syndrome – that's your diagnosis. Or is it? What if it's not postviral? What if the viral illness is not a clear trigger for the illness? Well, you've got alternatives: in the Mental Health chapter, you've got Neurasthenia, which of course was talked about back in the last, and previous to last century.

Helpfully, it excludes postviral fatigue syndrome but includes "Fatigue syndrome". So if you think someone's got a fatigue syndrome that's not triggered by a virus, should you be using this diagnosis? If not, one of these three: if you think that somehow, psychological factors have some role to play in your patient's diagnosis or in their illness, should you use one of these diagnoses, including some beautiful, historical, interesting syndromes such as Effort syndrome, Da Costa syndrome, whatever "Neurocirculatory asthenia" was in those days. But it gets actually worse than that because that's five possible diagnoses you can use and the trouble with these diagnoses is, you have to somehow guess that psychological factors have an important role to play in their aetiology – how on earth can you guess that when someone may be presenting five years after the illness started? So, difficult to make these diagnostic labels.

5:40

But actually, if you are more neutral – you don't know whether it's psychical or mental, you want to use a more neutral term – well you have got something you can use in ICD-10, in the

"R Chapter" - "Chronic fatigue, unspecified" which helpfully includes [R53.82] "Chronic fatigue syndrome NOS." You could actually use that if you don't want to jump off the fence as to whether this is physical or mental in the dualistic, in the *dualistic* mood.

5.59

It's confusing isn't it? And some of my junior staff would suggest that when you get this confused, as I am, over ICD-10, you are always left with a diagnosis – a self-diagnosis, of course, of senile dementia, sorry, senile, *senior* – dementia comes later. [Laughter]

So ICD-10 is not helpful and I would not suggest, as clinicians, you use ICD-10 criteria. They really need sorting out; and they will be in due course, God willing.

6.23

What about research criteria? Well about every three years, over the last twenty years, we've been reinventing in committee rooms – no longer full of smoke – of the great and the good, deciding what the illness is, with the CDC starting off in 1988; the Australians; the UK got involved in 1991; London ME criteria etc etc; even the Brighton (post-vaccinal) Collaboration's got involved now. So are they helpful? Let me just review are they? I'm not going to review them all, don't worry. I'm going to look at the CDC Revised Criteria of 2003. Let's see what this illness is.

6.56

Final minutes

24.30

So last of all, in my last five minutes - five minutes, John? Four!

What is ME? It was first described in 1956 by Sir Donald Acheson, in a Lancet Editorial, and he was describing actually a different thing than what I've just been talking about. He was describing epidemics of fatigue with prominent neurological signs and symptoms - something he later regretted doing because he thinks it confused the picture and I think it probably did.

So let's give you a bit of Melvin Ramsey, and this is the Royal Free Epidemic of 1955. This is Ramsay, and 74% showed objective evidence of involvement of the central nervous system, I'm not giving you the whole picture, just a flavour. Heavy involvement of the cranial nerves; objective evidence of brain stem and spinal cord involvement. *Paralysis* occurred, not just the face but other areas in just under 20%. In other words, this is a *different* illness, this is *not* the same. Do you see your patients with facial paralysis and do you make a diagnosis of CFS if you have a facial paralysis? So I'm suggesting that actually, the original definition of ME is different from what I've just been talking about.

25:45

How did this happen? I'm afraid we're responsible. There it is. Thirty years ago this very month, I think it was in this building – it didn't look like this in those days. We did it. We transmogrified, we changed, transposed epidemic ME into *endemic* ME. So actually we've got a

definition of a different illness that we have transposed onto this illness – which I think is where our problem comes from.

26.16

What message – and they also said at that conference – emphatically, this is organic. What's that word mean? Incurable, neurological disease. OK? Now, it may be right. It may be wrong. But what message does this give our patients? Now, here is the latest edition – you've seen outside – of "ME Essential". There are two levels to understand this picture – one: Brave attempts of a woman to cope with a severe, disabling, incurable disease – trying to live a normal life in spite of being ill. But what message does that give our patients, when we say to them "You have an incurable, neurological disease."? Is it more useful a message for our patients to say that or to say, "Graded Exercise Therapy is a safe and effective treatment, if it's done properly."? Because the two statements cannot be at this moment joined together.

27.28

And here's the evidence. A study again from GPRD of the effect of the doctor saying, "You've got ME." to patients, compared to saying "You've got Chronic fatigue syndrome." What we found was that those labelled "ME", their illness lasted longer than those labelled having "Chronic fatigue syndrome"; the ME patients had more consultations, both in general, and specifically, for fatigue with their general practitioner, in spite of the fact that before diagnosis (because this was a longitudinal study) there was no difference between CFS and ME in consultation rates or in fatigue consultations – suggesting that diagnostic labels we use, have meaning not just for us but for our patients, particularly when they look on the internet for what ME and CFS means.

28.22

We need to be very cautious in using these labels without adequate explanation of what they really mean and how we are going to help our patients.

28.30

So I'm going to conclude, to keep John happy. CFS/ME exists. No doubt in my mind, but it's hard to define. I would commend to you the broad-based definitions, rather than one with lots of symptoms. Both heterogeneity and comorbidity should be addressed, both in treatment and when looking at aetiology and it's very important that we are aware of what we mean when we give a diagnosis to our patients. Thank you very much for listening.

[Ends at 29:03]