

The Orwellian NewSpeak of M.E. and CFS Studies

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Chronic Fatigue Syndrome: The original “Orwellian” name for the illness. Had a focus group been convened to create a more dismissive name, they could not have done a better job. “Chronic” as in complainer, “fatigue” as in “yeah, I’ve been tired lately too” and “syndrome” as in “syndrome of the month.” It made a disease as serious as AIDS or MS sound silly, and made patients the butt of jokes all over late-night television. As of today there are at least six conflicting research definitions for CFS. From the standpoint of research, the name is useless. It is retained because it has great value politically - and great value for insurance companies.

Biopsychosocial school: Sounds good, but there is no such thing. To the extent that biological or social factors are introduced into the analysis, it is always to show how they impact the psychological results, or how a symptom that appears biologically caused is actually psychological in nature. British psychiatrists working on CFS use this term to mean they aren’t really psychiatrists working on CFS. But they are.

Cartesian dualism, or mind/body dualism: this is not particularly new or earth-shattering. There is a long-standing tradition in western medicine that the mind and the body are separate. Thus a physically caused disease is “real” and a psychiatric disease is not. However, after years of advances in understanding such disorders as schizophrenia and depression, we know that they, too, are physical. In this theory, however, the conclusion is turned on its head. The physical is psychological in their interpretations. If you question that premise, they will accuse you of Cartesian dualism and refuse to respond.

Actually, the philosophy behind the British psychiatrists promoting CBT and GET has more in common with pure extensionalism or postmodernism – I feel sick, therefore I must be sick. If I felt well, I would be well. Instead of melding the body with the mind, which is implied when an article begins with a discussion of the limits of Cartesian dualism, the authors end up with the mind ruling everything. At least, for patients.

Evidence-based medicine, as used by most researchers: In the AIDS and cancer communities, “evidence-based medicine” has a very specific meaning. It grew out of problems getting drugs approved for AIDS and cancer patients. The FDA process is rigid in its insistence on controlling for placebo effect and isolating the drug being studied. The first is immoral (and of questionable value) when the patient is dying- how can you justify giving a placebo when the patient wants the experimental drug? The second is bad science: it has become clear in both AIDS and cancer research that combinations of drugs work better than one drug alone. To study the drug alone, you must either use it in doses that are more likely to be highly toxic, or you won’t be able to measure any improvement. There are more sophisticated mathematical models available for testing the efficacy of drugs today, and the “evidence-based” approach is to use (for example) multivariate

models, boolean math, models from chaos theory – complex models used successfully in other fields - to determine the efficacy of a drug.

Evidence-based medicine is still a good concept that needs more debate when it comes to the way FDA approves or disapproves a pharmaceutical – and especially when it comes to non-pharmaceutical therapeutics, for which it can be impossible to devise a “placebo study.”

But that is not what is meant here by “evidence-based medicine.”

Cluster outbreaks of diagnosis:

[Most of the description of the CDC and the cluster outbreaks comes from Hillary Johnson, "Osler's Web"]

Surely if you were studying “swine flu” you would not ignore the patients who came down with it in Mexico this year – but that is precisely what CDC did with the mysterious outbreaks of similar diseases in the mid-1980s. CDC studies swine flu by examining the patients who have it. Suppose, instead, they combed the population for anyone showing symptoms of the disease. Since the symptoms of swine flu are virtually identical to those of the annual influenza outbreaks, you would have no way of distinguishing between those two groups. Whatever evidence you could obtain by focusing only on those diagnosed with swine flu would be lost.

Of course, the ability to study swine flu in this way comes from the agent having been identified. Such was not the case with the disease that would be named “CFS”. Had the agent for swine flu not been clear, would that disease be even considered a threat today? How many people would have to die first, and how would they identify it?

There was always a different path that could have been chosen. CDC could have shown respect for the reporting physicians and their patients and simply acted as it was intended to do – go out and write down everything that they could about the outbreaks. This is what Gilliam did in his 100-page study for Public Health of the 1934 Los Angeles General Hospital outbreak of what was then called “atypical polio.” Gilliam included 25 case studies described in detail so that future doctors might have a clue to connections more visible later. The report even added a map of the route each worker in the epidemic took from the parking lot to the place of work (which was one reason a type of polio seemed to be the cause, because they all passed through or worked in the polio ward).

The Holmes study of the CFS cluster outbreaks (1988) took 6 pages and described no patients at all. It simply took a disease that had been assumed to be the cause – chronic Epstein-Barr Virus – and renamed it “chronic fatigue syndrome,” then listed the symptoms they would have used for CEBV. The disease was conceptualized from Washington and poured onto the treating physicians and patients without regard to whether there was a fit or not. At least the Fukuda article (1994) suggested that future research should try to identify more homogeneous groups for study.

CDC refused to take the physicians’ word for the condition of their patients. They only

studied one outbreak in detail – the Tahoe/Truckee outbreak – and it was determined in Washington that the group would focus only on the specific symptom of “fatigue.” When they were through, out of roughly 150 patients who should have been included in the outbreak, the CDC insisted they could find no more than ten. Problem solved. There was no cluster outbreak of disease at all.

Instead, CDC insisted, the clusters were caused by physicians willing to confirm the patient’s own belief in his/her illness by giving them a diagnosis. Others learned a diagnosis could be obtained by that physician, and so they flocked to the site. (This has been reported by many people, most notably journalist Hillary Johnson, and I personally was told this by CDC.) CDC ignored the evidence that the patients being reported were from the same geographic vicinity.

There was no cluster outbreak; there were only outbreaks of diagnosis.

Physician-based studies:

The CDC now had a difficult task. It was charged with studying a disease that they insisted did not occur in cluster outbreaks. In fact, they had all but accused the doctors reporting cluster outbreaks of being quacks. So they created their own physician-based study, focusing on several areas but most notably Wichita, Kansas. The result was a very low estimate of the number of Americans – 10,000-50,000. And the bulk were upper middle class white women. The disease transitioned from simply “yuppie flu,” the derisive term picked by the media, to yuppie flu for women. CDC and NIH spokespersons went around the country expressing sympathy while insisting that this was a disease that struck upper middle class women trying to have it all. I first heard this thesis expressed at a 1996 conference. Dr. Reeves, the speaker, began with a slide of a woman in Victorian dress lounging on a fainting couch, her forearm delicately draped across her face. Good heavens! I thought. The next thing they’re going to do is tell us our uterus will shrivel up if we study science (a well-known shibboleth from the nineteenth century that was a good laugh-line to liven up a history class). Little did I know. (See the blurb on Beard and “neurasthenia” at the end of this piece.)

Population studies:

How else can you study an epidemic without revealing that it is an epidemic? You study cases that occur outside the cluster outbreaks. Deliberately ignoring the evidence available from cluster outbreaks, CDC chose at first to create a data set from a population-based survey in Wichita, Kansas. By 1998, CDC had notified the community that they now estimated that 500,000 American adults had the disease. However, Dr. William Reeves, head of the CFS program at CDC, refused to go public with this information until the study was published in a refereed journal article. That took five years.

In the meantime, Dr. Leonard Jason and a team of demographers at DuPaul University in Chicago conducted their own population study. In contrast to the CDC’s study, the

DePaul group used translators for different ethnic groups. The DePaul study, which is now pretty much accepted as the standard for CFS-Fukuda, estimated that 800,000 adult Americans had the disease. It did not differentiate on the basis of ethnic group or income, but it was slightly more common among women than men.

The Chicago study was published in 1999. The CDC refused to use it because the CDC had not conducted the study. CDC's Wichita, Kansas, study was not published until 2003. For several years the CDC continued to use the old estimate of 50,000 when their own studies had shown 500,000 – and Jason had shown 800,000.

If you take Jason's estimate for the prevalence of the disease among adult Americans, make the assumption that the prevalence is not increasing over time, then today that would be 1 million adult Americans suffering from the disease. That is the most accurate accounting we have. Where did CDC get 4-7 million?

“Evidence-based medicine” and “random controlled trials (RCT’s) in CFS studies:

After the publication of the Jason study, there was a great deal of discussion in the professional community about the superiority of population studies to physician-based studies. The biases inherent in the Kansas physicians' survey were, frankly, embarrassing after the Jason study was published. But that was not because there is something inherently wrong with physician surveys. That was because there is something wrong with poorly-conceived physician surveys.

British psychiatrists began to trumpet the use of evidence-based medicine and random controlled trials, or RCTs. Of course, this makes sense. They did not even have to defend it.

However, when used by British psychiatrists on M.E. and CFS, “evidence-based medicine” means merely a data set produced by the use of questionnaires on supposedly randomly selected patients.

This requires above all that the questionnaires themselves be valid predictors of who has the disease. Hence the new Reeves questionnaires, which produce a data set that is not representative of the ME/CFS population, but rather of a milder version of the disease plus patients with depression or some other cause of “fatigue,” is referred to as “evidence-based,” which to those knowledgeable about current medical research means sophisticated modeling techniques – but in this case, the modeling could not be more elementary. Almost all of these studies rely on simple correlations, with causation inferred after the correlation is determined.

For example: in the mid-1990s, Dr. Stephen Straus did a study comparing cortisol levels of patients diagnosed with “CFS” and those with major mood disorders, as part of his own theory that CFS was in fact a type of mood disorder. Unfortunately for Straus' theory, the study demonstrated the opposite: patients with CFS have unusually low levels of cortisol, whereas patients with major mood disorders have unusually high levels of cortisol. For a long time this research remained relatively buried, accompanied by a quick

study by Straus that had used a small sample to “prove” that cortisol-replacement therapy was likely to do more harm than good.

Early in this decade, however, a new theory emerged from the British psychiatric school. CFS correlated with low cortisol levels, they insisted, because the patients had been under too much stress. The stress, they argued, blew out the body’s coping mechanism, leaving it with too little cortisol. And that would be the argument that both William Reeves and James Jones would pick up to use at CDC.

The UK version of “evidence-based medicine” produces study after study using patients generally drawn from a psychiatric clinic to demonstrate that “cognitive behaviour therapy” and “graded exercise are the only therapies useful for CFS. Patients who refuse to “cooperate” with CBT and GET can be “sectioned” (involuntarily committed to a psychiatric hospital). This happens most frequently with young people.

The U.S. version of “evidence-based medicine” has been to

(1) create a set of questionnaires that they claim use the Fukuda definition, but they do not. They diagnose the new Reeves “international empirical” definition.

(2) bolster James Jones’ argument that CFS is a type of post-traumatic stress syndrome caused by adverse events early in life, including but not limited to sexual assault. As can well be imagined, such a theory should not be casually promoted without a great deal of certitude, because it makes it all too easy for schools or protective services to take young people with CFS away from their parents and put them in foster care.

Cognitive Behaviour Therapy (CBT): CBT is promoted by the UK’s public health system as one of only two approved treatment for CFS, and, since they insist it is the same thing, M.E. CBT generally consists of ten weeks of talking therapy during which the patient learns that she (it is most likely to be a “she”) is not really sick at all, but rather has been practicing learned “illness behaviours” that must be replaced by appropriate “wellness” beliefs.

Graded Exercise Therapy (GET): GET is the other therapy approved by British health as a treatment for CFS. Begun at some point during CBT, graded exercise allows the patient to begin to get re-conditioned again. The goal of CBT is to return the patient to full participation in society – including holding a full-time job. It should not be confused with basic coping skills or the “envelope theory,” both of which are designed to aid a person disabled by the illness adjust to his or her limits and gain a certain level of independence within that “envelope.” GET’s goal is to return the patient to normalcy. The research on CBT and GET generally omits information about the number of patients who drop out or why they did so. Anecdotal evidence from patients who have dropped out of those programs suggests that the reason why is that they were being made significantly worse – and in some cases, permanently worse.

MUS – Medically Unexplained Symptoms. This is insurance code, which has been

picked up by the British CFS/ME psychiatric industry to mean pretty much what it sounds like. Where it gets creative is the insistence that the symptoms are medically unexplained because they will never be medically explained. That's a bit of a leap in faith. However, the insurance company is having great success having this put into their contracts. As mental illnesses have often been limited to only 2-5 years of coverage, so two now many insurance contracts limit MUS conditions to 2-5 years of coverage. Nobody objects because nobody knows to object – until it's too late. Examples of MUS conditions used in the literature are lower back pain, carpal tunnel syndrome, TMJ pain, and fibromyalgia. But the poster child is definitely Chronic Fatigue Syndrome.

There is a fairly obvious rebuttal to the entire MUS concept as it is used by British psychiatrists and the insurance industry. Just because no one knows why a physical symptom exists does not mean we will never know.

We certainly accepted Parkinson's and Alzheimer's without knowing precisely what caused them.

Conversely, diseases such as polio, muscular dystrophy, and multiple sclerosis were all labeled "hysterical paralysis" before they were better understood. As late as the 1960s doctors were still diagnosing "hysterical paralysis" in women who would turn out to have M.S.

Another example of a physical disorder that was once thought to be psychiatric is "Cold Mother Syndrome" – autism. Autistic children, in general, are made uncomfortable by direct eye contact or physical touch. A mother sensitive to her child's needs would respect the child's concerns, even if it made her sad, and try to limit both eye contact and touching. Medical observers saw the correlation: autistic child, mother who makes less eye contact or touching. And then they assumed causation. Cold mothering caused autism. We will catch up to that one again later.

MUPSS – Medically Unexplained Physical Symptom Syndrome. That's a mouthful. There is evidence that the British psychiatric school of medicine, teamed with insurance companies such as UNUM, are trying to create a category for MUPSS in ICD-11 that would match to an MUPSS category in ICD-V. Watch this one.

Neurasthenia

George Beard, "American Nervousness," 1869 – Source of the word "neurasthenia."

Both Stephen Straus and Simon Wessely directly referenced a nineteenth-century physician named George Beard as the author of the term "neurasthenia," which has become Wessely's synonym for "CFS." If the World Health Organization (WHO) permitted it, Wessely would classify CFS in F48.0: neurasthenia. However, it's against the rules for a signatory nation to change the classification – and CFS is already coded as a neurological disease in ICD-10 - G93.3, with M.E. [The U.S. gets away with keeping CFS under "vague signs and symptoms" because we're still on ICD-9, almost a decade after almost every other nation in the world accepted ICD-10!]

Beard was an interesting choice to emphasize. Both Straus and Wessely believed CFS to be caused by upper middle class women trying to have it all. Beard wrote that allowing high school girls to study science leads to "arrested development" of either their nervous system or their reproductive system – not so for boys, because their reproductive system is comparatively simple. A sincere female student will end up with one of two outcomes:

1. Hysteria: normal nervous system, but abnormal reproductive system. The girl who studied science risked arrested development of her uterus – a shriveled uterus. Beard noted that a fellow physician in New York had measured the uteruses of three intellectual women and found them to be half-sized. [The more classic definition of "hysteria" is the "wandering womb." Apparently philosophers and physicians had a lot of trouble figuring out the female reproductive system ...] Indeed, two British psychiatrists had suggested in a pair of articles in the 1970s that M.E. was really "mass hysteria" - their thesis was basically based upon the evidence that the patients were female.

2. Neurasthenia: normal reproductive system, but a damaged nervous system. The girl will have a "nervous condition" the rest of her life – prone to the vapors, to strange moods, weak. Hence the image of a woman in late Victorian dress lying on a fainting couch with her forearm draped delicately over her forehead - the image that began Bill Reeves' talk on CFS at the 1996 AACFS conference in San Francisco.

At risk was the survival of the "American race." Already, Beard wrote, birth rates were down for "American" families. In contrast, the daughters of the "Celtic race" (Irish immigrants), unburdened by high school, had no problems with the vapors, and multiplied like rabbits. Beard feared that the "Celtic race" would soon overrun the "American race." The theory was immensely popular in the United States.

So that's the basis of an entire industry in "fatigue studies" among British psychiatrists. CFS is a condition caused by inappropriate coping skills, leading to the only treatment the NICE guidelines approve for British medicine – ten weeks of cognitive behavior therapy and ten weeks of graded exercise therapy. You must teach the patient she is not sick at all, and then you have to re-condition her after all those years in bed. That's it!

The CDC version, to which both Bill Reeves and James Jones subscribe, is that trauma in childhood predisposes the patient to develop CFS. This is a rather dangerous theory at a time when parents of CFS patients risk losing their children to protective services, but there it is. One would think the correct way to test for this would be to compare a group of people who grew up in the Bosnian War, for example, with a group who had a peaceful childhood. Instead, the diagnosis is made retroactively and, like the British psychiatric school, while hard evidence may be plucked from here or there to fit the theme, the thesis is entirely theory-driven. When Reeves did a study on genetics in CFS, he only used those genomes known to be associated with the body's ability to manage stress.

So - where did Reeves get the new estimate of 4-7 million (in contrast to the DePaul estimate of 500,000)? If you follow his work, that's a bit startling. He began by saying 10,000-50,000 in the early 1990s. In 1998 he announced at a CFSCC conference in Cambridge, Massachusetts, that he had raised the estimate to 500,000. Then in 2006 he was suddenly saying 4-7 million, which is what he uses today.

Either this is an epidemic that is spreading at a very rapid rate - or something is wrong with the way Dr. Reeves goes about getting his statistics. The last version of 4-7 million is what happens when you use Dr. Wessely's British (psychiatric) estimate to the American population. So the CDC has now adopted the British psychiatric definition - no physical symptoms but depression can be included. The worst cases are lopped off - along with everyone from the original Tahoe/Truckee outbreak - and a lot of people with depression are included. But the rest of the world thinks CDC is still using the Fukuda definition - at least, that's how Reeves is promoting the questionnaires with which the CDC came up with its new data sets.

The transition is complete. CFS as a disease exists completely independently of the very people the term and definition was commissioned to describe.

Big Brother and the Thought Police would have been proud.

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<http://cfsknowledgecenter.ning.com/profiles/blogs/the-orewellian-newspeak-of-me>

Table 1: Preliminary Model for a Medical Case Definition of ME/CFS

SYMPTOM CATEGORY	TYPES OF MEASURES	CRITERION	DIAGNOSTIC PATTERNS
<p>Neurologic Manifestations</p>	<p>Imaging Tests MRI: Clinical Lesions EEG: Slow wave pathology; Alpha spiking in temporal Parietal lobe VEP/EP: Kindling Behavioral Tests 12 Cranial Nerves Test Finger Tapping Test Heel/Shin Test Or 2 Neurocognitive Deficits Questions 26-34</p>	<p>Neurological _____ 1 lab result or positive behavioral test Or 2 Neurocognitive Deficits</p>	<p>Benign: Individual was once symptomatic in relevant categories but is currently remitting. Usually within 10 years of first onset of fatiguing illness and manifesting as ICF, Atypical, or CFS-like illness. Characterized by highest variability of symptomology.</p> <p>Relapsing-Remitting (Moderate): This includes two or more exacerbations (relapses) with or without complete recovery of function.</p> <p>Relapses (periods when symptoms worsen) alternate with remissions (when symptoms are stable). Remissions may last months or years and may or may not include recovery of function. Relapses include Severe and Moderate symptomology and can reoccur spontaneously or be triggered by an infection such as influenza or stressful life event. Progression may be subclinical.</p> <p>Secondary Progressive (Progressing): Includes more than one exacerbation with persisting and/or worsening of symptoms during remissions.</p> <p>This pattern begins with relapses alternating with remissions, followed by gradual progression of the disease. Periods of Severe and Moderate levels of symptomology are interspersed with overall worsening symptom.</p> <p>Primary Progressive (Severe): Includes one or more exacerbations with continued progression of severity of symptoms without return to baseline. Fewer exacerbation periods and less variability of symptoms.</p> <p>The disease progresses gradually with no remissions or obvious relapses, although there may be temporary plateaus during which the disease does not progress.</p>
<p>Autonomic Manifestations</p>	<p>Imaging Tests SPECT: hypoperfusion Tilt Table Test: ↓BP ↑HR Behavioral Tests Orthostatic Intolerance Romberg's Sign 8-12 Standing Test Or 1 Autonomic Manifestation Questions 26-34</p>	<p>Autonomic _____ 1 lab result or positive behavioral test Or Autonomic Manifestation</p>	
<p>Endocrine Manifestations</p>	<p>Lab Work Cortisol Level Behavioral Measure Fatigue And 1 Neuroendocrine Deficit Questions 39-46?</p>	<p>Endocrine _____ 1 lab result or positive behavioral test Or Endocrine Manifestation</p>	
<p>Immune Manifestations</p>	<p>Labs Work Low NK cells and activity Or 1 Immune Manifestation Questions 47-50?</p>	<p>Immune _____ 1 lab result or positive behavioral test Or Immune Manifestation</p>	
<p>Post-Exertional Malaise</p>	<p>Stress Test Persantine and Antidote Or 1 Post Exertional Deficit Question 9 (See Autonomic)</p>	<p>Not Required PEM _____</p>	
<p>Sleep Disorders</p>	<p>Sleep Lab EEG: Absence of REM activity with Alpha intrusions Or 1 Sleep Deficit Questions 10-14</p>	<p>Not Required Sleep _____</p>	
<p>Pain Manifestations</p>	<p>Headaches Myalgas/Arthralgias Or 1 Pain Manifestation Questions 10-14</p>	<p>Not Required Pain _____</p>	