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When one actually has true ME, G93.3 (Ramsey, Hyde) all of the other terms/names being bandied about become extremely problematic.

**-->CFS (R53.82) has absolutely nothing to do with ME (G93.3).**

If everyone paid careful attention to the science, facts, details, and differences, that would become crystal clear to all.

The 'lumping' together of the two began in the UK with the Wesseley School (WS), and that silly myth persists. Only these days the WS doesn't have to work very hard anymore, as illness ignorant patients, coupled with the multitude of erroneous info on the internet--which no one bothers to verify--keeps it alive and growing.

Blending together an extremely debilitating neuro illness that has been on the WHO books since 1969 (41 years) and which starts, presents and ends very differently from a tiny little syndrome written based on fatigue (CFS, written b/n 1988-1994, so 26 years) is beyond absurd. Yet that is what has happened. The fact that so many--including so called 'experts' (many self-proclaimed)--fall for this is mindblowing. They clearly are ignoring way more than just terms/names - they are ignoring formal criterias and definitions, WHO classifications and ICD Codes, and the many other differences and details.

And why has this happened?

- 1) The WS has been well-paid for many years now by the insurers like Unum to help them deny patients claims. To obfuscate.
- 2) The USA 'CFS' crowd decided they wanted something that 'sounded more serious', so they hijacked ME, G93.3.

Trouble is they each START, PRESENT and END differently.

But instead of separating apart the many different types of MISdiagnosed patients currently falling under the vague label of 'CFS' and determining what each really actually has - they instead tacked 'CFS' (Fukuda, et al) onto ME, a severely debilitating neuro illness.

Despite the fact that the vast majority of patients did not, and do not, meet the formal definition(s) of ME (Ramsey, Hyde).

Very little research has been done in the past 26 years, and the bulk of it has been done by little groups here and there, sporadically, and on whatever aspect they wanted to study. There has been no large, worldwide effort. No large databases established. (Tho I did ask the WPI to start one. However, they q's they ask are too few and too broad, etc.)

**As a result, nothing significant has been discovered in all of these 26+ years. And never will be, doing things this way. Why?**

-->Because mixed patient groups will only and always produce mixed data - which is helpful to no one.

Nothing moves along further because they aren't even just mixing apples with oranges - they are mixing fruit with nuts. Without adhering to strict, rigid scientific protocols from start to finish, no study small or large will ever be replicated by other scientists.

**-->And without 100% replication by other researchers, nothing will ever advance beyond the beginning stages.**

Furthermore:

ME has long been thought to be caused by an enterovirus. CFS by a retrovirus (which 'fits' with its classification all along by its authors/originators, the USA CDC, under zoonotic, vector-borne, rickettsial. Think bug bites. The XMRV is, I've read, a mouse retrovirus.) CFS happens slowly and can't even be diagnosed for 6 months, and even then: only when everything else has been crossed off the list. ME starts with a 'sudden onset viral event'.

-->CFS remains a 'diagnosis of exclusion'.

00>'CFS' has never, to date, been proven to be viral. The USA CDC site has always referred to it as infectious.

ME starts with a 'sudden onset viral event' that first damages the brain, brain stem and CNS. Hence its classification by the WHO under Brain, neuro, CNS!

'CFS' comes on slowly, and doesn't include CNS. Instead is a tiny little 'syndrome' based on 'fatigue'.

And on and on and on..... The differences and details make quite a long list!

The bottom line is:

It's about far, far more than just names/terms. It's **about what those different names/terms MEAN, and which criteria or definitions they are attached to.**

It's also about patients and Drs who haven't updated their thinking in 26 years.

It's about patients who are coded differently in their files by their Drs, but instead 'choose' to say they have 'CFS' (!) Or now: 'ME/CFS'.

It's about wishful thinking and is not based on fact or reality. It is 'groupthink' at it's worst. And there's a whole ever-broadening online group now--thanks to the interent-- who believe everything they read but never bother to verify anything. They prefer to stick with their personal 'favorites', opinions, myths, misperceptions, etc.....

Its' about patients who will never give up their support groups because they've become a lifeline, even tho they are harming themselves by clinging to incorrect info and old beliefs. Many of these folks, when tested and evaluated more thoroughly by different Drs, prove to have things treatable! That any individual would choose to stay in a comfortable rut when they could recover their life and health is just shocking.

The entire situation is beyond absurd at this point. **People are so embedded in their years-long beliefs they can't see the truth.**

Or they simply don't want to - because they are comfortable in the holes they'd dug themselves into.

**-->It all impedes serious, large scale, long term, strict protocol research efforts.**

I have big doubts XMRV will prove helpful in any big way, for anyone. I suspect it will got the route that Epstein Barr did - many are exposed (like 90% of the population) but it's not the cause, or even carrier, etc.

XMRV, described as a mouse retrovirus, is nothing for anyone with true ME, G93.30 to even think about, if it's true--as the Drs who identified it in the early parts of the last century determined--that it is caused instead by an enterovirus.

Again: Not even apples vs oranges. But fruits versus nuts.

Yet our disease (ME, G93.3)--not syndrome!--is held highjack now by this casual group who think details and differences don't matter.

It's a hell of a situation that leaves all of us ME-defined patients in a limbo state. This is unconscionable.

I will not live to old age. I am too ill and my body is way too damaged. I am down to approx 2 hours of stamina per day. You won't see true ME patients at conferences; we're all too ill to travel. A few of us struggle mightily to stand up for ourselves and our illness, but at great costs to our already horrific health. Imagine how it feels to see things spin even more wildly out of control each year, as you go downhill more and more, while others who clearly do not have what you do say they do now. What a colossal joke.

'Cept we ME-defined aren't laughing; we're crying while we live our lives of quiet and isolated desperation.....

I hope you understand better now.

Some serious updating and eye-opening is necessary now by the 'CFS' and the ever-expanding 'ME/CFS' crowds.

It would be helpful if you and your group--and others around the world who also mix and confuse terms and their classifications--would remember these few key points below.

For clarification and in chronological order:

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- ME is G93.3, Neurogenic and post viral. Sudden onset. Formally classified by the WHO under **Brain, CNS, Neurology**. Since 1969.

- 'CFS/ME' is the term created by the UK Wessely School's (WS) for their made up **psychosocial illness MODEL**. It's usage in the late 1980s to early 1990's.

**It has no WHO classification or ICD Code.**

- 'CFS' was written after the USA Lake Tahoe epidemic, b/n 1988- 1994, by the USA CDC. It was written to describe what at the time they thought was an Epstein Barr situation. It was never written to describe ME, G93.3. The USA CDC has always classified 'CFS' (Fukuda, et al) under R53.82, **fatigue, ill-defined, vector-borne, zoonotic, 'diagnosis of exclusion', etc**. It remains a 'syndrome' (i.e., group of symptoms) based on 'fatigue'. Slow onset, post infectious. It is, at best, a very weakened, watered down version of ME, G93.3. At worst: a joke.

NOTE: The WS and the USA CDC (Reeves) have collaborated many times in the past and are working together still to push their latest collaboration, their 2005 'empirical definition' for CFS, which if they are successful will land 'CFS' under a 'mental' classification in the 2012 updated version of the DSM5, instead. If corrective action isn't taken now, ME, G93.3--because it's being casually and incorrectly lumped together with CFS in various ways--will become subsumed, as well. **This cannot be allowed to happen.**

- 'ME/CFS' is another 'blended' term made-up term by by the 11 authors of the 2003 ME/CFS Canadian Criteria (CC).

**It has no WHO classification or ICD Code.**

- It's creation makes 'CFS' patients (Fukuda, et al, R53.82) happier because their 'fatigue states' sound more serious.

- But it infuriates true ME patients (G93.3) because it weakens and waters down their severely debilitating CNS illness.

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Additional NOTES:

1 - In the WHO classification system:

**Two different classifications (e.g., R's (R53.82) and G's (G93.3) cannot be mixed together, and**

**No illness (or syndrome) can be classified in two places.**

2 - Which brings us to the 'post viral CFS' debacle in Britain that also took place b/n the early 1990s and 2004, and which has caused the UK contingent to cling tightly to the 'ME/CFS' misnomer ever since, however inappropriately.

This misguided action somehow added 'post-viral CFS' (only--not nos CFS) to the UK's version (only!) of the ICD10. It is believed that an Andre L'hours at the WHO was involved. Apparently both he and Britain's CMO(s) at the time approved this action. (As a USA citizen, I am not understanding how a CMO would have that autonomy? And the full details of this joint venture have proven extremely difficult to resurrect. Others - feel free to flesh out the details!)

But this addition of 'post viral CFS' (only) to G93.3 was a deplorable mistake and has caused massive misunderstandings around the globe as a result. The internet has helped with this, as so many believe whatever they read without bothering to verify it. To date, no one anywhere in the world has yet proven that 'CFS' is ever post viral. Again, the USA CDC has always referred to it as post infectious.

-->This UK action above to be UNdone ASAP, if it hasn't already been.

-->Re-read **red sections** above.

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In summary:

It is absolutely essential that each and every patient be diagnosed **correctly and properly**, upfront and in a timely fashion, and based on sound medical evidence, the patient's thorough and complete medical history, symptoms, observations, testings, formal criterias or definitions, and more. It is critically important to recognize and note:

- . The way an illness STARTS, PRESENTS and ENDS matters.
- . That a few 'similarities' do not mean a 100% match.
- . That the DIFFERENCES are what need to be paid attention to!
- . That 100% replication of studies, adhering to strict scientific protocols and done by outside researchers, must occur, and
- . Each illness, or syndrome, needs to be studied separately, as mixed data derived from mixed patient groups produces only mixed data - which helps no one.
- . And different terms/names mean different things to different people and fly in the face of logic because they ignore well established criterias and definitions, WHO classifications and ICD Codes, etc.

Throwing everything into the pot may be quick and easy, but it nevertheless creates a stew with many mixed ingredients. At this point, in this illness ignorance situation, it

would be much more informative and useful to work backwards now and carefully pull out and identify and categorize all of the ingredients in the pot - and then study each separately to learn their makeup, and how they might or might not contribute to the whole. Some may be unnecessary. Some may be poisonous. Some may add a bad taste. Etc.

It is time for SCIENCE to drive all efforts, not a mixed bag of patients who view the whole thing as more of a social networking situation. That approach will never provide succinct answers.

Most Sincerely,

LK Woodruff, USA