

Wetenschap voor Patiënten (Science to patients)

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Webinar 51: Criteria and diagnosis, part 1

Prof. Leonard Jason. Broadcast September 2th 2014

What would you call this disease and why?

The British started calling this illness ME many years ago and there's been a regression back to CFS in 1988 through the CDC in the USA. I think there's been a movement to change that, and actually some people are calling it ME/CFS as a transition term. But I ultimately think this illness should be called ME, for Myalgic Encephalomyelitis. I think that's the legitimate name for this illness. In a sense it got hijacked thirty years ago and it needs to revert back to that original name.

Does the name CFS trivialize this illness and why?

The name CFS is a terrible term with which the CDC came up many years ago, in 1988. If you think about someone who is coughing and you would say he suffers from 'chronic cough syndrome', people would say 'who cares, everybody coughs. It just isn't a big thing'. However if we call it bronchitis or emphysema, people would say 'that really sounds as a significant issue'. So the name counts. And you can't use a name for an illness that trivializes a condition. Chronic Fatigue Syndrome is one of those names that ultimately has to change.

Our group actually did some research looking at attributions. We called it ME and we gave a case description. Then we gave it the name CFS and after that we attached the term Florence Nightingale Disease. We did the same case study and we found that names do make attributions and they do significantly make a difference in how one thinks about those cases. We did this research with medical interns as well as psychology undergraduates and we found, attributions undergo changes, based on the terms that are used to describe cases.

What is wrong with the CDC-criteria?

The CDC-criteria are often considered to be the same as the Fukuda 1994-criteria. They were assembled by consensus of a group of people. I think consensus based case definitions contain problems, specifically with four symptoms required out of eight possible ones. You can miss some of the cardinal symptoms of this illness. For example, three cardinal symptoms are post-exertional malaise, memory- and concentration problems and unrefreshing sleep. However if a person has four other symptoms and not these three cardinal symptoms, he can still get the diagnosis CFS. That's the major problem with an illness category when the cardinal features of the illness are not required to be diagnosed.

What criteria do you use in your current research?

Our group actually looks at several criteria and tries to have people fill out a questionnaire. And then we actually look at how a person meets the 1994 Fukuda-criteria, how they meet the new 2011 ICC-criteria for ME, as well as the Canadian ME/CFS criteria. So we try to compare and contrast those three. But I must say, there's limitations with all three. And consensus based efforts are probably not really the best way for us of characterizing this illness.

What's the difference between your primer of 2013 and the ICC/ICP of 2011-2012?

The IACFS/ME put out a primer that uses the Canadian consensus criteria of 2003. We found that there had been a good amount of research that at least had suggested that this particular case definition selected a smaller group of patients that had more functional impairment. So we decided to focus our primer around the case definition that had been around for ten years. It most importantly specified the core cardinal symptoms of post-exertional malaise, memory- and concentration problems as well as sleep difficulties. So that's why we decided to kind of write a primer and focus it around a case definition that we thought was an improvement of the Fukuda 1994-criteria. In fact there was another case definition, the ICC, that did come out in 2011 and 2012, but there hasn't been as much research done at that particular case definition. So we decided to use the one that had a little bit more been used by the research community.