

## Wetenschap voor Patiënten (Science to patients)

It is permitted to disseminate all transcripts within the project Wetenschap voor Patiënten (Science to Patients), under the explicit condition that the source ME/cvs Vereniging, <http://www.me-cvsvereniging.nl/> is clearly mentioned.

### Webinar 52: Criteria and diagnosis, part 2

**Prof. Leonard Jason. Broadcast September 9<sup>th</sup> 2014**

#### **What do you think to be the cause of ME?**

There are certainly lots of opinions about the cause of ME. There are individuals who certainly have a viral kind of beginning, sometimes mono(nucleosis). There are other people that have some type of accident that causes their onset into this illness. There are other people who have some type of environmental toxin or exposure to molds.

So there actually are quite a few different types of things that seem to precipitate this illness. It's very possible that these individuals might have some genetic predisposition to this particular ME illness. Just as other types of chronic illnesses have been found to have some genetic predisposition. But I would say that at least at this point, it sounds like there are a number of triggers that could be the precipitants of individuals manifesting ME.

#### **What is the reason for the stigma that is associated with ME?**

There's a terrible stigma associated with people who have ME. A lot of people wonder why is this the case? Our group at DePaul University has actually put together a scale that measures stigma. So that we can get some clues as to what's going on. We certainly have a society that values energy and stamina and endurance more than anything else. It's probably more important than even money, if you can believe it. And if you don't have those qualities of energy, you are a person who's probably more discriminated than any racial or any other type of group in our country. Because energy is what makes the American dream. People who have fatigue are seen as being deficient somehow.

And the reason is that everybody feels fatigue at some point. Sometimes it is through a marathon race, but sometimes it's through having several jobs. Ordinary fatigue that most people experience is something that probably goes away when they go on a vacation. Or when they're not stressed because of so many responsibilities. So most people think of fatigue in completely different ways than patients who have ME. So when a patient with ME kind of says that he doesn't have energy or endurance or stamina, others react "I have all that things I have to do, and I keep doing it. Why can't you?". And worse than that: 'You don't look like you're sick'.

The combination of those different characterizations leads to incredible societal negative attributions towards patients, which makes them almost like the 21st century lepers. Like how it might have been like two hundred years for people with that other disease.

## **Do you diagnose ME by Exclusions? What do you include?**

I think that it's important to diagnose ME not just by exclusions but also by inclusions. We need to understand a person has core symptoms of this illness, like for example post exertional malaise. That has to be there for this illness to exist. And yet some of the questionnaires say you need to have 24-hour difficulties after you've exercised with some symptoms including fatigue. Those questionnaires are problematic and I'll tell you why.

A lot of people don't push themselves because they're so sick. So they don't have to experience post exertional malaise, because they've learned in some ways to really hold off. And they form a little bit of an energy bubble, as their 'envelope' - about which we'll talk another time. So it's possible that some individuals would experience post exertional malaise if they were pushed. If they had to do exercise, if they had to do the daily tasks that most people do. But since they're not doing that, some of them don't even experience it. So if you ask the question if they do experience it, they'll say no. But the reality is they would have it, if they would have to do daily activities.

So all I'm saying is that we have to be so careful to phrase the questions in the right way to tackle these types of complex symptoms. If you put a person on an exercise bicycle and really do a challenge, then you'll find post exertional malaise. Particularly not after one day but after two days. Because after one day they're able to push themselves enough to look good and some of these oxygen exchanges will be ok. But when you do the testing it's the second day that you see the post exertional malaise. So again both with exercise, with challenges as well as with self-report questionnaires, one has to be so careful about how one asks the questions. So that we identify people who really have the core symptoms.

Clearly you don't want to bring people into your studies, or into your practice who have another illness. So if they have MS, if they have cancer fatigue, if they have other types of fatiguing illnesses that are due to medications, you want to exclude them. If there is a psychiatric reason for their fatigue, like major depressive disorder with melancholic features, you want to exclude them as well.

You want to find people with ME, solely ME and not something else. To get a diagnosis of ME, I think you have to have three cardinal symptoms. Post exertional malaise, neurocognitive problems like memory and concentration difficulties, and unrefreshing sleep. Those symptoms I think need to be there. Not that there aren't other symptoms that could be there as well. Like some of the immune, neuroendocrine and autonomic. But I would say the three that I first mentioned are critical.

## **What is the DePaul Symptom Questionnaire? And what is its focus?**

Over the last fifteen years our group at DePaul University has been working on developing ways of using self-report questionnaires to assess patients' symptoms. Our most recent effort is called DePaul Symptom Questionnaire. We've actually put that on an electronic system called 'red camp', that is available now to anybody in the world and which they can download. This is a 54 item questionnaire that according to us measures some of the current symptoms of many patients that have these types of illnesses.

Each symptom is rated for frequency and severity on a five-point scale. We've been doing some basic research on this questionnaire, making sure it has some good reliability and also

validity. We feel pretty comfortable that this scale could be used by people both in clinics as well as in research settings. And we have some investigators from different parts of the world that are currently using our scale.

### **Can the DePaul Symptom Questionnaire be used by anyone?**

The DePaul symptom questionnaire could really be used by anybody. It could be given to patients at a clinic, it could be given to researchers, to their subjects, the participants in studies, where patients could fill it out. The thing that we like about the questionnaire is that we have built an algorithm which forms a pattern of looking at the responses. After a person actually fills in the particular questionnaire we can score which case definitions they meet. That gives us the ability to use the questionnaire to focus on people in terms of how many symptoms they might have for the critical case definitions.