

Wetenschap voor Patiënten (Science to patients)

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Webinar 50: Introduction / experience with ME

Prof. Leonard Jason. Broadcast September 2th 2014

My name is Lenny Jason and I am a professor of psychology at DePaul University in Chicago. I'm also the director of the Center for Community Research. I've been at DePaul University for the past 39 years.

How did you get involved in ME?

I initially got involved in ME-research in the early nineteen nineties. At that time people were talking about this disease as the 'yuppie flu'. What I found was that the CDC had done some prevalence research, called the four-city study. And they had estimated that fewer than 20,000 people had this illness. I was very skeptical of that research, and when I looked at their methodology as a research psychologist, it was significantly flawed. For example, they had referred people into their study who had been identified by doctors as having ME. And yet as we know lots of physicians don't even think this illness exists. So how can they refer such people into their catchment prevalence study? So basically looking at that research I was skeptical, realizing the CDC at that time was getting several thousand phone calls every month about severe fatigue and possibly ME. And I decided that I would try to work with some colleagues on a prevalence epidemiology study with adults.

What kind of research did you do regarding ME?

After looking at the research literature, we found that basically there were better ways of estimating prevalence than through ascertainment methods by physicians. So myself, Judy Richman and several other colleagues wrote a NIH grant. We were able to get funding to actually sample 26,000 people. And in that large sample, a community-based sample, we tried to find out how many people might have ME. What we found was that the rates were much higher than what the CDC had estimated. So by the mid-late 1990s we were able to make projections that approximately a million people had this illness. That was one of the first large studies our group did. But it took us ten years to work on that basic epidemiology, from writing grants, getting it funded, doing the research, to publishing it. So it is a long term commitment to do this type of research.

What are the most important discoveries you made?

I think one of the important things that we learned was that not less than a million people had this illness, rather than the 20,000 which were estimated. So it wasn't really a rare disorder, but the 'yuppie flu' was really a myth. The people we found having this illness did not tend to be yuppies. In fact we found people who had lower incomes had more likely to have this illness. So folks belonging to minorities, colored people, were more likely to have

this illness. Those were important findings, both the prevalence as well as the numbers. And that led us ultimately to make statements about this illness that we really needed to have more public resources devoted to it. In part because it wasn't a rare disorder, just affecting a bunch of middle-class individuals who were possibly lingering or doing something else. This was a serious illness, affecting a lot of people, many of them not having resources and suffering other disadvantages besides this illness.

What research are you into currently?

In terms of the work we're doing currently, certainly we thought that in terms of epidemiology it was important to find out the prevalence rates for adults. We're now in a way trying to do some community-based prevalence studies with young people, with pediatric ME. And that work we're going to be doing for the next five years. We're also going to be doing research on college students who have mononucleosis and will test them when they're healthy. Looking at what happens when they develop mono, and trying to follow them as to which ones recover and which ones don't. So with Ben Katz at Children's Hospital in Chicago I'll be doing this work on those two very large projects over the next five years.

Is your research psychological or also physiological?

The current research that we're doing implies that we want to get a look at all the different parameters. In terms of what are risk factors for those who end up getting this illness versus those who don't. And particularly looking at them before they get ill. That's a very important factor. Some research that we're just publishing for example looked at mononucleosis in youth. We basically found that there were no psychological factors predicting as to which ones would get more severe ME in the future. What we found was that the severity of the illness they got actually was the only thing that was a significant predictor. So that's an important factor suggesting that there might be more biological factors that involve both the initiation of this illness as well of its maintenance.