

Wetenschap voor Patiënten (Science to patients)

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Webinar 56: Population and social impact

Prof. Leonard Jason. Broadcast November 4th 2014

Is the risk of ME higher due to gender, race, genetics or occupation?

Some people have asked whether ME is different in different parts of the world. Certainly there was an initial myth that ME was more prevalent among yuppies, among people who are white and had higher income. That myth is not true. So we actually know that ME tends to be more common among individuals who have a lower income. That is a very important thing. In the United States we have also found that ME tends to occur more often in minorities, of people of color. So yes we've also done a community based study in Nigeria, and we've actually found rates of ME to be higher than in the United States.

So we think ME occurs in many different places around the world. In terms of which particular groups have higher rates than others we're not sure, but certainly in the United States we've found some differences. And certainly people of lower socioeconomic status are more likely to have this illness.

Whether ME is race related is something that we really don't understand well. Some of the symptoms of ME, for example orthostatic intolerance, do seem to be different in African-Americans versus Caucasians. In terms of us being able to definitively understand some of these factors is unclear. We did find for example Latinos in the United States had the highest rates of ME than any other group. And particularly among women Latinos versus men Latinos. That was kind of interesting. We've also found that Latinos who had been more acculturated, who had been more into American society, had differential rates than those who had not been acculturated.

We do think that genetics probably make certain people predisposed toward having a lot of chronic illnesses, and ME is probably a good example of that. We still have a lot more research to be done on that, but I think eventually we will be able to conclude that. That's my guess. Whether ME is somehow higher in particular groups versus other groups, I think that that's something future research will be able to understand better. I think presently we still are trying to understand some of the risk factors for this illness. The best research that's going to help us understand some of these genetic markers is to actually to look at genetics in healthy people and look over time, to see which ones develop ME and which ones don't. And then look at some other risk factors, both environmental as well as biological. That's really the way we're going to disentangle the role of the genes versus the environment, and see the roles of this different things.

What did you find in long-term studies about recovery rates?

There have only been a few long-term studies involving individuals with ME. It does seem like individuals who have longer illness tend to have more cognitive difficulties and more symptoms. Actually we are working on a paper now, trying to look at people who have had this illness for a longer period of time. There really aren't a lot of studies that have been published in this area. But it does look like length does increase some severity issues.

What functional impairments do you see in people with ME? How severe can they be?

Patients with ME have as severe functional impairments as any of the major illnesses, including cancer. And on and on in terms of different very significant chronic illnesses. So these are very sick patients. Patients who really need the best medical care, and patients who are often provided the worst. We see some of the worst functional areas that people have is the physical capacity to do things. Endurance, stamina, that's probably the area where people have the greatest limitations. Sometimes cognitive confusion, where a person basically can't remember things or can't remember why they're doing something. And that often makes it very difficult for a person to be in a work setting. There's the physical impairment of being able to do things consistently over time and then the next day continue to do that. You see lots of impairments particularly with this post exertional type of testing. With cognitive challenges too it seems to be really very difficult to think and remember things and focus on things. There are neurocognitive and post exertional functional impairments that we see in patients.

What is the cost to the individual and society?

Economic analyses have been sometimes done and in America our group has estimated that the cost might be up to twenty billion dollars a year, for the types of problems that patients have with ME. But the real cost is to the patients who are in a situation that they have one of the most severe illnesses that we know of, and they're actually provided the least comprehensive treatment. So here are individuals who have one of the most difficult problems we can think of and they're questioned about the validity whether they really have an illness. Can you think of anything worse in terms of a personal cost than being so sick and having people questioning whether you really are ill or not.

Funding by the government has been at very low levels. Really needed are places you can go to, to get diagnosed and treated. And in the United States these generally don't exist. If you have cancer, if you have MS you can go to specialized clinics, and you get the best diagnosis and the best treatment. But for example, I live in Chicago and there really aren't physicians who are specialists who treat patients with ME. And that's a problem. So we need to have the type of healthcare that involves services which are available to patients. And right now they don't have that services nor do they have the research dollar investment to provide the types of data that we need to find out which pharmacological treatments are most effective with patients. So in both the research arena and in the service delivery arena we're provided with very low amounts of resources, given the severity of this problem that affects our populations.

What can be done to improve the deplorably situation that patients with ME are faced with?

In terms of what can be done for patients with ME, I actually spent the last year writing a book called 'principles of social change' that Oxford University Press has published. And in that book I really try to indicate what other social change movements have done to bring about change. Including the civil rights movement and other types of groups, like the women's movement. And ultimately it's endurance, it's staying committed to something over long periods of time, it's basically having community coalitions that work and try to really deal with the power abuses that occurred. And it's really looking at some other structural issues that need to be faced. We need to organize. We need to be more effective. We need to basically be able to change the status quo, because the status quo is not working for patients with ME. It's only by us collectively being involved in action that the situation really is going to change. As it has changed for many other illness groups, particularly the people with HIV/AIDS, who really have demonstrated that it is possible to bring about a sea of change in treating and appreciating people who have that illness.

What kind of social support may help?

We need social support for patients that involves the family, parents who protect their kids, guardians, spouses, parents who are able to stand up for the rights of individuals who are sick. And also people in educational settings, as well as social service settings, medical settings and within work settings who provide for the special needs of patients. And we all have to recognize that first of all this is a legitimate illness and we have to be willing to accept some of the limitations that patients have. We also have to validate their experience and work with them in terms of what they need. Individualized approaches are critical. So really the entire social network has to be mobilized. That might involve the person's brother or sister, a person's father or mother, a person's grandparents, the people who work at their church, the people who are their medical associates. Everybody has to come together in a team that makes their life more livable, and actually has the respect and services that they need to make a quality of life. To bring about a change is going to involve not just the patients who have ME, because many of them are sick. It's also going to get involved the people who are well. the people who care, the people who are spouses. It's going to involve a social change movement of people saying we're not going to take it anymore, we're going to make a change. And it's going to be thousands and thousands of people working together to say 'this cannot exist the way things are'. And that's going to be the start of the social change movement. That's not going to be in one country, it's going to be in multiple countries.