



**National
Multiple Sclerosis
Society**

**MS Learn Online
Feature Presentation
Health Services Research
Nicholas LaRocca, PhD**

Tracey>> Hello, I'm Tracey Kimball

Tom>> And I'm Tom Kimball. Welcome to MS Learn Online. When we talk about MS research we usually talk about what is being done on the clinical side to find treatments and someday a cure for MS. In recent years that research has been paying off with new treatments and improved health services for people with MS.

Tracey>> Yes but how many of us have access to these new treatments and services. Nicholas LaRocca works for the National MS Society and he spends his time in an area called health services research.

Tom>> In an interview with medical correspondent Kate Milliken, Dr. LaRocca explains what health services research is and what they've been learning.

>>Dr. LaRocca: Health services research looks at the organization of healthcare, the financing of healthcare, access to healthcare, the quality of healthcare, and it's very important because you not only want those effective treatments, but you want the right people to be

able to make use of them, have them available and for them to be affordable.

>>**Kate:** I was going to say, I also have to believe, too, that people with MS, whether it be, whether it be people looking at this, on trying to take kind of a good, hard look at how MS is affecting people's daily lives, is there anything in that outlet that you're working on?

>>**Nick LaRocca:** Yes. Well, for example, we have what's known as a longitudinal study known as the Sonya Slifka Longitudinal Multiple Sclerosis Study, and it's following a large group of over 2,000 people with MS over time, and it's looking at a wide variety of the impacts of MS.

So, how it affects everyday life, how it affects the way in which people perform their everyday activities, what kinds of problems they run into.

Also, how they feel about their life, how they feel about the quality of their life. What issues they have in reference to employment. What issues they have in reference to access to healthcare, and things of that nature. So that if we can understand what the impact of MS is on people, particularly in their everyday life, it helps us to understand how we need to intervene, how we need to help people to soften those impacts.

I mean, one that comes to mind right away is a study that's being done by Bob Buchanan at Mississippi State University, and he just recently completed a national survey of people who are caregivers for people who have MS. And we've done a lot of studies with people who have MS. We haven't looked at the people who -- we call them caregivers, we call them care partners, but they live with the person who has MS, they're the person who doesn't have MS, but they share the MS, and they share the responsibilities for dealing with the limitations of MS. And we don't really know that much about what life is like for them, what the experience is like for them, what the

pressures are, what their needs are. And so Bob is looking at many of those issues, so that in the future we can focus more on those people, what their needs are, and to try to help them to live with MS in a better way than they do at present. So, that's one example.

Another example is a study that's being done by Michael Trisolini, who works for RTI International, which is a think tank., and he's looking at MS adult day programs. And these are programs that are run in various places, some of them are in hospitals, some are freestanding.

And they're an opportunity for people with MS who aren't working and who usually are pretty severely disabled to come together with other people who have MS, to usually get some kind of physical therapy or other types of therapy. But also to share, to talk to both professionals and other people with MS, to learn different skills, to work on cognitive problems, and things like that.

And Mike is doing two things: He's looking at the way those programs are set up so that we can hopefully in the future we can expand those programs so that more people can have those kinds of opportunities; and he's also looking at what are the benefits of participating in those types of programs. Are these programs really helping people to remain healthier, to stay out of nursing homes, and to actually perhaps reduce the amount of healthcare that they're utilizing? And so that's another type of study in the realm of health services research that if successful could have a major impact throughout the country in the opportunities available for people with MS.

>>**Kate:** If people wanted to see the results of the studies or how they're coming along, is there a place they could access them?

>>**Nick LaRocca:** The best place to look would be at our website, which is www.nationalmssociety.org, that we have brief summaries of our research projects on the website. And also in the scientific

literature, in scientific journals, when a study is completed, one or more look for a more complete report of what's going on.

And the people who are interested can access an index of those articles by going to a website called “PubMed”. It's run by the National Library of Medicine, and it's very easy to use. You just type in what you're interested in and it will give you a listing of articles that have been published in that area. And it's a good place to start.

And then if you find something that's of interest, you can very often obtain the full length article, if you wanted to really go into it in-depth. So, there are a couple of places where you can find that kind of information.

>>**Kate:** In some ways I have to believe it's really hard for you guys on this realm to be doing these types of studies due to the fact that MS is such an individual disease. So, in light of trying to kind of pull together statistics to make an impact and to be conclusive, has that been difficult for you?

>>**Nick LaRocca:** It's challenging, but I think that there are two ways to look at it. One is that you want to look at what an overall trend might be. And so for that you want to look at a large group of people. But in addition, you want to be able to capture the individual flavor of a given person's life. And in order to do that we need to ask a different type of question and in a different way, so that people are given the opportunity to just more or less talk with less structure about what their experiences have been.

And so we've really done a little bit of each, and if you can combine the two, then you have a much richer picture of what's going on. And also, when you start out to do, let's say a survey, where you're asking those very structured questions, one of the first things you do is to really sit down with people in an open-ended way and to ask them about their experiences so that you don't just sort of go off on

your own, but that you really are guided by what they have lived through and what their concerns are.

>>**Kate:** So, in light of your research, what would you say has been the most positive trend that you have discovered?

>>**Nick LaRocca:** I think that one of the most positive trends has been the fact that people are connecting with one another more than they did years ago, and there are several reasons for that. One is technology, that people have the ability to connect with others through computers and through the Internet. Also, people have been given opportunities to connect with one another through, for example, the National MS Society, through MS World that has online chat groups, so that people are able to exchange ideas, compare notes in a way that was really not possible let's say even 20, 25 years ago.

I think that's been a very, very important step. I think people have learned a great deal from that. And as a result they've challenged the professional community to be more on top of what's happening and to be able to answer more difficult questions than they did in the past. Because people are smarter, they're more knowledgeable, they're learning more, and I think that's a good thing for everybody.

>>**Kate:** I would say, also, that building an army of people who are kind of in the battle together also is something that is very positive for the emotional side, kind of the MS world, and I think that's something that can't really be measured.

>>**Nick LaRocca:** I think you're right, and I think we certainly see that in the MS Society, There really is a movement that has gotten started in the last few years, and part of it is reflected in the research that shows this connectedness among people, which is a relatively recent development.

Tom>> I was not aware that this type of research was being done and yet I can understand it's importance.

Tracey >> Yes! Thank you Dr. Nick LaRocca for helping us to understand the important field of health services research.

Tom>> And thank you for watching MS Learn Online. We hope to see you again soon!