

Statistics and Risk Assessment

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Judy asked me for my thoughts on Alasdair Coles' brief article on "Myths and Facts for MS" which was in the May/June issue of New Pathways. I was a little surprised by the article on two counts. First of all I was amazed that a big name, mainstream MS clinician and researcher like Dr Coles would be contributing to New Pathways and secondly I was somewhat taken aback at the starkness of his pronouncements. To me, it is very positive that Dr Coles contributed to New Pathways. I hope he and other knowledgeable neurologists will see New Pathways as an excellent vehicle for conveying useful information on MS to a large group of people with MS and will contribute in the future.

However, I also hope in the future he will take a little more time with his comments and couch them in a more user-friendly fashion. I would stress that the information that Dr Coles provided was not wrong. It was simply not the best way of presenting it and, because of this, I expect his very bald "facts" gave many people the wrong idea of what he was trying to say and angered them.

In his first three "Myth versus Fact" topics, he looked at the variability of MS progression, the possibility of MS remaining benign (i.e. not progressing), and the relationship of MS and longevity. All of these subjects relate to potential negative effects of having MS. For each of these topics, Dr Coles naturally depended on statistical studies of MS populations for his statistics-based facts. Summaries of these studies, in the form of article abstracts, are readily accessed on at PubMed (<http://www.ncbi.nlm.nih.gov/sites/entrez?db=pubmed>) which contains millions of abstracts.

When it comes to statistics, the most important thing to understand about such data is that they have little relevancy for accurately predicting outcomes for an individual. Dr Coles pointed out that one study showed that, after 20 years, half of the studied MS population had progressed to secondary progressive MS. This does not mean a person with MS will have secondary progressive MS after 20 years. They may never get it or they might progress to that advance disease

state in 10 years or less. There is no way anyone can know the fate of any individual irregardless of available statistics.

That said, statistics are still very valuable for the individual, not to mention for their doctors and their insurers. Statistics provide us with accurate risk assessments and this is most important for helping to guide one's actions. Risk assessment has everything to do with survival and we are constantly doing risk assessments every time we contemplate an action, from crossing the street, to changing lanes in our car. Such genetic programming is crucial for survival and, over the millennia, most of those who were not good risk assessors were eliminated from the gene pool due to their bad and fatal decisions. This resulted in a human population of excellent risk assessors.

When one is diagnosed with MS, it is important to be knowledgeable about the risk statistics associated with the disease and these are not intuitive. The risks mainly involve acquiring various disabilities that restrict one's capacity for different actions but extend all the way to death. Thanks to many longitudinal studies of populations of persons with MS, such as the French study mentioned by Dr Coles, a person newly diagnosed with MS can obtain reasonably accurate risk assessments in regards to various consequences of having MS. Such a quantitative risk assessment can and should guide that person's actions in regards to what they do about their MS.

Dr Coles has done us a favour by providing some quantitative risk assessment information on key potential problems associated with MS. It is very worthwhile for a person just diagnosed with MS to know that, if they take no actions regarding MS, their risk of substantial disability in 20 years time is about 50/50. Those are not good odds! Dr Coles also noted there is a 50/50 chance a person with MS will die earlier than they otherwise would have if they did not have MS. Finally Dr Coles' statistics made it clear that one has a very low chance of not eventually accumulating some disability over 20 years with MS (i.e. very few remain "benign" over a lifetime). All this information is not good news and hence the backlash against Dr Coles' article. However it is useful news which can potentially be very motivating and lead to great benefits

To me these somewhat sobering statistics should strongly encourage a person newly diagnosed with MS to become very proactive and do everything reasonably possible to reduce the risks of MS-related disability and early death. This is the time to take action as opposed to 10-15 years later when the accumulated disabilities have become very problematic and the chance of

reducing the risk of further disability is much slimmer. One does not want to do a risk assessment about crossing the road when they already in the middle of the road.

Given the very real and rather ugly risks people with MS face, they need to let these established risks associated with MS guide their actions, just like they let risk assessment guide most facets of their life. These actions have to centre on strategies to slow and halt disease progression and the accumulation of disabilities. Unfortunately no one, including one's neurologist, provides a rational and comprehensive list of actions to take when one is diagnosed with MS. The only thing a neurologist will recommend to potentially reduce risk of progression is a prescription for one of the MS drugs. The current data indicate that such a strategy will, at best, only slightly reduce the risk of disease progression for most.

This is where Dr Coles falls down. He obviously knows the high risk of accumulated disability and early death for persons with MS. He is also well aware of the low efficacy of the MS drugs. In spite of all this knowledge, Dr Coles fails to help his patients explore non-drug related therapies. I would be willing to bet he has not ensured every one of his MS patients has a circulating vitamin D level near the top of the normal range (120-150 nmol/l) despite all the information linking vitamin D deficiency to MS and the fact that such a therapy would be extremely easy and inexpensive to institute.

I would also bet Dr Coles does not advise all the first degree relatives of his MS patients to maintain a high level of circulating vitamin D in spite of knowing they have much higher risk of MS than the general public and that the current database leaves little doubt that adequate vitamin D can prevent MS in most cases. There are many other potentially valuable actions that Dr Coles is not telling his patients about. It is fine that Dr Coles provides statistics on disease effects of MS and this is a service to persons with MS. However it is not fine that, despite the grim nature of the statistics, he does not act on them as much as he could.

In my next column I'll try to provide a long term action plan for someone just diagnosed with MS.