Truly benign multiple sclerosis is rare: let’s stop fooling ourselves - Commentary

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Yes, many clinical neurologists, myself included, have, on discussing the implications of multiple sclerosis with a newly diagnosed patient, emphasized the possibility of the illness being mild and have quoted figures of about 20% prevalence of benign MS after 15 or more years of illness. Remember that 20 years ago we had no treatments to offer the person with MS and compassion meant offering some hope. I did phrase the debate to stimulate dialogue; that is the aim of the Controversy series.

The group in Florence lead by Maria Pia Amato have in the last five years convincingly demonstrated that in that subset of “benign” patients with mild motor disability, 45% had significant cognitive deficits predictive of worsening disability in the next five years.[1]

Observing patients over 35 years of practice, one has become less sanguine about using the term benign. Indeed now I rarely use it partly because we now have an expanding range of therapies, we can monitor disease activity more accurately and adjust treatments appropriately. We, the neurologist and the patient, have both become empowered.

In differing ways both debaters are right. Amato has described the “pseudo-benign” patient resulting from the effects of a high cerebral lesion load causing cognitive deficits relative but sparing motor tracts. What her group has shown is that, even in patients with no relapses and stable mild disability, regular careful assessment including yearly or bi-annual MRI scanning is necessary. Increasing cerebral T2 lesion load, without overt symptoms or apparent signs, requires a change of therapy. We cannot be completely at ease with the apparently benign MS patient.

However, even if we accept that not all patients with an EDSS of 3.0 or less after 15 years have benign MS, Hawkins is also right, truly benign MS is not rare, only less common than previously supposed. Keeping patients with mild MS returning to a hospital clinic filled with wheelchairs is not an easy task. Hawkins makes the entirely valid point that we can only estimate the prevalence of benign MS from community based studies and quotes the Olmstead County[2] and Goteborg studies.[3] The estimate of 10% benign after 20-30 years of illness seems realistic and in keeping with the long term follow-up in South Wales.[4] In addition there have been no long-term studies of potential cases detected in screening familial MS and other mild cases who may rarely attend neurology clinics [5].

What we have learned in the last ten years is not to use the term benign MS, based only on the EDSS, prematurely, not to be complacent or over-reassuring; clinical vigilance is important in the whole spectrum of MS disease activity.

References