

Decision making in MS: factors affecting engagement in treatment choices

Multiple sclerosis (MS) is an autoimmune disorder of the central nervous system, and the most common chronic neurological condition affecting young and middle-aged adults. The majority of people diagnosed with MS (85%) will initially experience a 'relapsing-remitting' course, with periods of increased symptom activity followed by full or partial resolution (Ebers, 2001). Over time, physical, cognitive and sensory function can worsen. Disease-modifying therapies (DMTs) have been found to be effective in relapsing-remitting MS, reducing new lesion formation and disease progression (Kieseier et al., 2011). The number of DMTs available for MS has increased over the past 20 years, and each offers a distinct side-effect profile and, potentially, differences in clinical benefit. Complex decisions therefore need to be made not only about whether to start treatment, but also which treatment to choose.

Involving patients in treatment decisions is increasingly encouraged (e.g. Department of Health, 2005; Institute of Medicine, 2001) and has been linked to a number of positive outcomes. It can improve clinical outcomes, leading, for example, to better treatment adherence and possibly better health outcomes (Hibbard and Greene, 2013), reduced healthcare consumption, with fewer diagnostic tests and referrals, and decreased use of healthcare services (Rieckmann et al., 2015). From the perspective of those with MS, shared decision making can improve satisfaction with treatment (Little et al., 2001) and MS knowledge (Stacey et al., 2014). Yet, despite these benefits, some choose not to engage in decision-making processes.

In a neat, clear study in this issue of *Functional Neurology*, D'Amico and colleagues examine the role of clinical and demographic variables in patient preferences regarding engagement in treatment decisions. Consecutive newly diagnosed people with MS were invited to take part, and 100 were enrolled. Each indicated whether they preferred active involvement, collaborative involvement or passive involvement in medical decision making. Sixty wanted either an active or a collaborative role in their treatment decisions. The 25 people preferring to be actively involved had greater physical disability (as rated using the EDSS) and had experienced more relapses than the other two groups. This was in line with the view that those who experience more disease activity may become more involved in their own healthcare. No group differences were seen in age, disease duration or years of education.

After identifying the factors predicting engagement, we then need to consider how people with MS can make the best, most informed treatment decisions. In this, they can be supported through patient information and educational initiatives (including the excellent patient-focused treatment information provided by many national MS societies) and effective clinician-patient communication (Coulter, 2012). Greater understanding of how MS affects risk evaluation is also becoming increasingly important. Previous work has suggested that some people with MS, particularly those with secondary progressive MS or with greater physical or cognitive impairment, may show decision-making deficits, and so may struggle, for example, to adjust to different levels of risk (Kleeberg et al., 2004; Muhlert et al., 2015; Radomski et al., 2015). This may have implications for adherence, as those who fail to adhere to DMTs tend to devalue treatment efficacy and inflate treatment risks (Bruce et al., in press). Evaluation of risk/benefit ratios of treatment in MS can however improve following educational programs (Heesen et al., 2011). Further work is needed to assess whether those most likely to experience MS-related changes in risk perception benefit most from these programs, and what influence they have on treatment adherence and patient engagement in the long term.

In summary, the findings by D'Amico et al. help to indicate those most likely to engage in treatment decisions. In addition, they shed light on those who could receive more information about the benefits of engaging at an early stage. Risk evaluation may be affected at later stages in the disease. Combined, these studies suggest that educational interventions aimed at those with low activity early in the disease course, or that focus on optimizing risk evaluations later in the disease course, may prove effective strategies to improve patient engagement and patient outcomes.

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