Background: Individuals with multiple sclerosis (MS) have to cope with uncertainties concerning diagnosis, prognosis, and drug therapy. This makes disease-related decisions a challenge, starting with the decision of whether or when to go through the diagnostic process. Many important decisions follow, mainly related to drug therapies. Evidence-based patient information has been promoted for people with MS in order to address uncertainties and to allow informed decision making based on the best available research evidence. In recent years, our group has performed a number of pre-studies and systematic reviews on important related topics. We have developed and evaluated three educational programs and two decision-support tools.

Methods: Two randomized controlled trials (RCTs) have been performed to evaluate an educational program on relapse management and a decision aid on immunotherapy. Also, a questionnaire study was performed to evaluate a concise information leaflet about MS diagnosis. Currently, an ongoing RCT is evaluating an educational program for people with early MS. Also ongoing is a controlled trial evaluating a program in rehabilitation clinics on immunotherapy. Different end points have been used to evaluate the interventions’ efficacy. Results: In the trial evaluating the decision aid on immunotherapy, we found no differences between groups. In contrast, the educational program on relapse management resulted in important changes in relevant outcomes. The information leaflet was perceived to be well balanced and assessed as highly understandable and important. The two trials evaluating educational programs on immunotherapy and early MS are still ongoing. Preliminary results will be presented. Conclusions: Rigorously developed programs aiming at facilitating decision making for people with MS are feasible and effective. A number of methodological issues have arisen. Therefore, recently a special interest group on “patient information” has been founded within the European Network of European MS Centers–Rehabilitation in MS (RIMS) to discuss these issues and to further develop and evaluate programs to support informed choice for people with MS.

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